

**STIGMA, HIV/AIDS TREATMENT SEEKING BEHAVIOR AMONG  
YOUTH LIVING WITH HIV IN KAMPALA CITY, UGANDA**

**BY**

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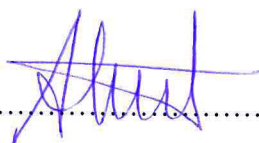
**A THESIS SUBMITTED TO THE DIRECTORATE OF RESEARCH AND GRADUATE  
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## DECLARATION

I, Kiwanuka Anthony, declare that this thesis presented for examination for the PhD degree of Makerere University is my original work. To the best of my knowledge, this thesis has never been presented to any institution for any academic award. I have fully acknowledged and disclosed the academic materials used in the development, discussion and presentation of this study. I do fully acknowledge all those whose works I have used; it is clearly indicated as the work of others, in which case the extent of any work carried out jointly by me and any other person is clearly identified.

Signature .....



Date 24-11-2023

## APPROVAL

This thesis entitled “Stigma, HIV and AIDS treatment- seeking behavior among Youth living with HIV in Kampala City, Uganda” presented for the award of a Doctor of Philosophy degree has been written and submitted by Kiwanuka Anthony with our approval as the supervisors.

We hereby certify that this thesis has been prepared to our satisfaction and that it is worthy the award with our approval as the candidate’s university supervisors.

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Signature 

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## **DEDICATION**

I dedicate this dissertation to all young people living with HIV in Uganda and beyond. Find life in appreciating your status and seeking early treatment. May the good Lord richly bless you all!

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## **ACRONYMS**

<b>AIDS:</b>	Acquired Immune Deficiency Syndrome
<b>ART:</b>	Anti - Retroviral Therapy
<b>ARV:</b>	Antiretroviral
<b>ASHM:</b>	Australasian Society for HIV Medicine
<b>AYA:</b>	Adolescent Young Adults
<b>CBT:</b>	Cognitive Behavioral Theory
<b>CDC:</b>	Centers for Disease Control and Prevention
<b>GARPR:</b>	Global AIDS Response Progress Reporting
<b>HAART:</b>	Highly Active Antiretroviral Therapy
<b>HIV:</b>	Human Immunodeficiency Virus
<b>IDU:</b>	Injecting Drug Users
<b>NCHSR:</b>	National Center in HIV Social Research
<b>NGO:</b>	Non-Governmental Organization
<b>NSP:</b>	National strategic plan
<b>OAFLA:</b>	Organization of African First Ladies
<b>PG Väst:</b>	Positiva Gruppen Väst =Better living
<b>PLHIV:</b>	People living with HIV but not AIDS
<b>SDGs:</b>	Sustainable Development Goals
<b>STI:</b>	Sexually Transmitted Infections
<b>STD:</b>	Sexually Transmitted Diseases
<b>SRH:</b>	Sexual and Reproductive Health
<b>STSB:</b>	Stigma Treatment Seeking Behavior
<b>TFR:</b>	Total Fertility Rate
<b>UNAIDS:</b>	United Nations Joint Program on AIDS
<b>USA:</b>	United States of America
<b>VCT:</b>	Voluntary Counseling and Testing
<b>WHO:</b>	World Health Organization
<b>YLWHA:</b>	Youth Living With HIV and AIDS
<b>YLWH:</b>	Youth Living with HIV

## LIST OF PUBLICATIONS AND ACCEPTED ARTICLES

- Anthony Kiwanuka, Lena Andersson, David K. Mafigiri, and Eddy Walakira, Impact of stigma on HIV treatment - seeking behavior among the youth living with HIV and AIDS in Sub – Saharan Africa: Critical Review Literature. **HIV AIDS Rev** 2021; 20, 2: 90-95DOI: <https://doi.org/10.5114/hivar.2021.107219>.
- Anthony Kiwanuka, Lena Andersson, David K. Mafigiri, and Eddy Walakira, Barriers of HIV treatment – seeking behavior among youths living with HIV in Uganda: A Qualitative Study.**HIV AIDS Rev** 2022; 21, 1:43 49DOI: <https://doi.org/10.5114/hivar.2022.112711>
- Anthony Kiwanuka, David K. Mafigiri, and Eddy Walakira, Experiences and ways people living with HIV and AIDS deal with their lives; (WKRO-02019-11-1401. R1) DOI: <https://dx.doi.org/10.4314/ahs.v21i4.15>African Health Sciences, Vol .21 Issue 4, December 2021
- Anthony Kiwanuka, Lena Andersson, David K. Mafigiri, and Eddy Walakira, Unifying social work and faith – based communities in combating stigma: Paper for Social Work, HIVAR-00395-2021-01. Submitted to: International HIV related problems, HIV and AIDS review Journal.Article accepted. In Press.
- Examining the national education framework: Case study of adolescents and youth living with HIV and AIDS in Mbarara- Uganda. Submitted to HIV AIDS Reviewer International Journal. Pending for corrections
- Adolescents, HIV, and AIDS service uptake in Uganda: Social Work Policy Paper. Submitted to HIV AIDS Reviewer international Journal.
- Challenges in accessing HIV and AIDS services among persons with Disabilities: Systematic review of research carried out among persons with disabilities living with HIV and AIDS in Uganda. Submitted to: International HIV related problems HIV and AIDS review Journal.Submitted to HIV AIDS Reviewers, international Journal.**Article accepted**

## **ABSTRACT**

This study sought to discover to what extent stigma affects HIV and AIDS treatment-seeking behavior among youths aged 18-24 in Kampala city. It also examines how anticipated stigma and non-disclosure of HIV status affects health-seeking behavior, and the experiences of living with HIV and AIDS. The study employed qualitative approaches involving purposive selection of study participants who included youths living with HIV. Data was collected through in-depth interviews, Focus Group Discussions, and Key Informant Interviews. It was analyzed using thematic and content methods that were phenomenological. This study was guided by theories of stigma including Goffman and Deacon's sustainable theory of health – related stigma as well as cognitive behavioral theory and coping.

All the youths in this study suffered self-stigma the first time they were diagnosed with HIV. They further felt other forms of stigma namely: internal, social, and discrimination. Being HIV positive was associated with punishment for bad behavior. Apportioning blame to HIV positive youths as self-inflicted by the community was common, thus, affecting youths' urge to seek treatment. Youths' fear of rejection and discrimination pervaded all aspects and their lives; from home to clinics, and community. Seeking treatment was not a common practice among HIV positive youths. Fear of rejection, lack of disclosure, denial and being asymptomatic, belief in witchcraft and other spiritual beliefs were key barriers to seeking treatment. This study highlights that the youth felt most stigmatized in comparison to other groups. Interactions and negative experiences in government healthcare settings contributed to a reduced engagement around seeking healthcare.

To combat stigma and discrimination, interventions must focus on the individual, environment and policy levels. What is needed now is the political will and resources to support and scale up stigma-reduction activities through health care settings in Uganda, to engage youth into empowerment groups of self determination and social change, work with social workers' organizations and use law to advance legal protection. The key recommendations from this research include the empowerment of the stigmatized group, i.e. the YLWHA, as well as their involvement in the design and implementation of prevention programs. Furthermore the focus of health education for behavior change communication strategies are family members or those with significant relationships to YLWHA, and health care providers, who were the major groups found to discriminate against PLWHA.

## **CHAPTER ONE: BACKGROUND TO THE STUDY**

### **1.0 Introduction**

This study set out to explore the effect of stigma on HIV treatment-seeking behavior of HIV-positive youths in Kampala city, between 18 and 24 years of age. Stigma includes perception, manifestation, interpretation and existence. HIV prevention and treatment-seeking behavior is conceptualized to include the perception of being HIV-positive, adherence to medication, mental health literacy, accessing healthcare services, as well as coping with stigma and its consequences. The following sections present the background to the study, the statement of the problem, the purpose of study, the objectives of the study, the research questions pursued, the significance of the study, the justification and scope of the study, the theoretical framework of the study.

### **1.1 Background to the study**

Over a billion young people are living with HIV and AIDS worldwide, with 23.5 million found in sub-Saharan Africa (McKinnon & Vandermorris, 2019). The impact of stigma on youths has many consequences, including forced isolation, dropping out of school, and postponement of starting antiretroviral treatment, prescribed to HIV-positive patients. Such challenges may hinder the access to HIV treatment (Lowenthal et al., 2014). Globally, stigma is a major obstacle to effective HIV and AIDS prevention and care. Non – disclosure of HIV status, in the context of HIV and AIDS, is a unique factor compared to other infectious and communicable diseases. It tends to create a “hidden epidemic” based on socially-shared ignorance, fear, misinformation, and denial (Collins et al., 2015; Lowenthal et al., 2014).

This is particularly more intense in sub-Saharan Africa, where a combination of inadequate health system is entangled in poor legal and ethical frameworks (Campbell, 2021). Issues concerning the impact of stigma are not yet addressed. Therefore, research studies are needed to thoroughly understand the consequences of stigma at all levels, and its effect on HIV prevention, treatment, and care, as it is directly related to different socio-cultural settings in Sub-Saharan Africa (Jackson-Best, 2018; Skovdal, 2019). In addition, more than twenty years down the road, HIV and AIDS is no longer a localized disease but a nation-wide problem irrespective of geographical location. While there has been a lot of progress in combating and understanding it, a lot of challenges still

remain. There is still no vaccine or cure for the infection and the number of people who are infected by HIV continues to relentlessly rise (Uganda National Policy on HIV 2007).

There is evidence to suggest that stigma associated with HIV and AIDS can limit access to care and treatment services by influencing one's decision to get tested for HIV, to obtain adequate healthcare and on the proportion of People Living with HIV that disclose their sero-status to a sex partner (Anywar et al., 2020). This, however, is limited as far as youths are concerned (Mwale & Muula, 2017; Papageorge, 2021). Therefore, understanding the impact of stigma on HIV prevention and treatment-seeking behavior for this group could contribute towards increased access and utilization of the available services.

The Human Immunodeficiency Virus (HIV) remains a major public health challenge in Uganda and generally worldwide, and a persistent risk to young people/adults (King et al., 2021; Mwale & Muula, 2017; Wen et al., 2018). In 2010, more HIV infections in developing countries occurred among adolescents and youths than in any other age group (Goldenberg et al., 2012; Mitchell et al., 2020). The status of the epidemic in Uganda, including trends in prevalence and incidence in the general population, indicates that every year, more than 50,000 Ugandans discover that they have HIV (Mitchell et al., 2020). Epidemiological data for the youth population of the present study, (ages 18 – 24) are not routinely reported. However, data for the adolescents and the youth population combined, i.e., data for people between ages 13 and 24, shows that this combined group makes up the largest age group of newly diagnosed individuals.

This comprises 39% of all new cases (Nabaggala et al., 2018a). These newly diagnosed young people, who account for 16% of the population with HIV in Uganda, require specific considerations from health-care providers because of the vulnerabilities attached to their youth. However, it seems like HIV and AIDS treatment-seeking behaviors among the youth in Kampala have not been empirically established; more so with the influence of stigma. Sustainable Development Goals (SDGs) i.e. Good health and well - being and other health frameworks and protection of the youth from HIV and AIDS and other Sexual and Reproductive Health (SRH) (for prevention, care and treatment of STIs and HIV and AIDS) concerns basing on Uganda Development plans; health policy strategies and frameworks.



HIV spreads rapidly both within countries and across their borders. It affects people regardless of gender, geography or sexual orientation. In many countries, the HIV epidemic is still considered ‘low’ or ‘concentrated’, that is, confined mainly within groups at especially high risk, including males who have sex with males, people who inject drugs and those in the sex trade. An epidemic is considered ‘concentrated’ when less than 1 per cent of the wider population but more than 5 per cent of any ‘high-risk’ group are infected (Kimera, Vindevogel, Rubaihayo, et al., 2019a).

In some countries of South-East Asia, such as Indonesia, Nepal and Viet Nam, epidemics are exploding among those who inject drugs and commercial sex workers, the two of whom are under the age of 24 (Nxumalo et al., 2015). In China, home to a fifth of the world’s people, serious concentrated epidemics have emerged in several provinces and HIV is rapidly moving into new groups. When HIV spreads to the wider population (i.e., when more than 1 per cent of the total population is infected), the number of infections tends to rise rapidly. Such ‘generalized’ epidemics, found in Africa, parts of Asia, Central America and the Caribbean, account for at least four out of five new infections worldwide (Swahn et al., 2019a).

In 12 countries of Sub - Saharan Africa, at least 10 per cent of those aged 15 to 49 are estimated to be infected with HIV (Kalembo et al., 2013; Mwale & Muula, 2017). Infections in these regions are among young people aged 18 to 24. In Botswana, South Africa and Zimbabwe, it is estimated that more than 60 per cent of boys aged 18 today have been infected with HIV during their lifetime (Mbonu et al., 2009).

Over 1.3 million Ugandans are living with HIV; prevalence among individuals aged 15–49 currently stands at 5.9% (Harrison & Li, 2018). Of note, those 18–24 years of age comprise 33% of the population, but account for nearly 50% of the country’s HIV and AIDS cases (Schuyler et al., 2015). Out of this, people on ART are estimated to 860,000 persons. “Pre-ART” Co-trimoxazole (henceforth prophylaxes) and ART have improved dramatically the life expectancy of people living with HIV and AIDS in Uganda, and ART scale-up has resulted in over 72% of these Ugandans receiving ART (Schuyler et al., 2015). However, the success of these drugs is highly dependent on adherence to medication and retention in care to slow the progression to AIDS; these lengthen survival, sustain viral suppression, and prevent drug resistance and loss of treatment options (Kimera, Vindevogel, Rubaihayo, et al., 2019b). Research from resource-poor

settings documents show youths have lower medication adherence and seeking health – care services than adults (Landefeld et al., 2018a). ?

A 2015 comprehensive review of studies focused on youths in sub-Saharan Africa identified multiple levels of barriers impacting HIV treatment-seeking behavior (Ramos et al., 2018a; Turan et al., 2016a). These included socio-demographic factors (e.g., poorer adherence among older adolescents as well as those living in spaces with less privacy such as foster care or orphanages), as well as structural and economic factors (e.g., limited access to food, high cost of transportation). The political instability further limited access to HIV care. There are also psychosocial factors (e.g., limited caregiver supervision, small support networks), individual factors (e.g., forgetfulness); treatment-related factors (e.g., high pill burden, negative side effects, challenging transition between pediatric and adult HIV treatment services). Individual resilience factors (e.g., good adaptive skills and positive expectations for their future were associated with better adherence) (Kimera, Vindevogel, Rubaihayo, et al., 2019b).

A 2018 systematic review of studies focused on youths in Sub-Saharan Africa reported similar findings, identifying stigma, ART side-effects, lack of assistance, and forgetfulness as important barriers; facilitators included caregiver and peer support, and youth having knowledge of their HIV status (Kimera, Vindevogel, De Maeyer, et al., 2019a; Nxumalo et al., 2015). Few studies from Uganda report youth-seeking treatment, adherence to ART and some studies indicate serious adherence problems (Kimera et al., 2020; Kimera, Vindevogel, De Maeyer, et al., 2019b). Some of the barriers noted included treatment holidays (i.e., breaks in ART adherence); delays in disclosure of HIV status by caretakers; stigma, especially in schools and work places; diminishing or lack of clinical support (Bernays et al., 2017; Zuurmond et al., 2020); and living in urban and rural areas (Kimera et al., 2020).

A study from one of the partner clinics (3rd Congress of Joint European Neonatal Societies (JENS 2019), 2019) and study of Swahn (2015) among HIV positive youth in Uganda showed that 71–74% of participants did not reach clinically meaningful levels of adherence and seeking treatment. Similar levels of poor adherence have been noted in other studies focused on adolescents and youth in Uganda (Kimera, Vindevogel, Rubaihayo, et al., 2019b; Sam-Agudu et al., 2016a; Schuyler et al., 2015) and other SSA countries (Helms et al., 2017; Turan et al., 2017).

Uganda currently counts approximately 170,000 Youth Living With HIV and AIDS (YLWHA) and figures are expected to rise as more youth remain highly vulnerable to the infection (Schuyler et al., 2015) and as access to Antiretroviral Therapy (ART) and other HIV treatment services increases (Harrison & Li, 2018). This group's increased life expectancy urges for a better understanding of their psychosocial situation and Quality of Life (QoL) (Kimera et al., 2021; Kimera, Vindevogel, Rubaihayo, et al., 2019b). Quality of life is a framework used in supporting people living with a chronic condition since it focuses on the general wellbeing and satisfaction with life in different life domains that may be affected by the condition (Bijl-Brouwer & Malcolm, 2020; Bilinski et al., 2017; Kvåle & Murdoch, 2021; Turan et al., 2017).

It is important to explore barriers and facilitators to seek treatment, health services and care for those infected with HIV. Improving the conditions at clinical centers can positively affect the HIV treatment-seeking behavior among the youths. As proposed by Kumar, YLWHA should have equal access to education, treatment and care for their special needs to enhance their physical, emotional, social and personal development (Kumar et al., 2020; Swahn et al., 2019b).

Still, Uganda has a roughly estimated 6.5% HIV prevalence (Swahn, 2015) and is one of two countries in Africa where HIV rates are increasing instead of decreasing (Swahn, 2016). Certain groups are disproportionately burdened by HIV within Uganda and include young women, commercial sex workers, men who have sex with men, and youth living in the slums of Kampala (Swahn, 2016; Swahn et al., 2019). For example, HIV prevalence among sexually active youth living in the slums of Kampala (13.9%) is higher than the national prevalence (Swahn et al., 2019b), and HIV infection may be exacerbated in this population by a lack of adequate infrastructure, food scarcity, and limited or no parental oversight (Culbreth et al., 2019; Swahn et al., 2019b, 2019a).

The Government of Uganda has put in place policies aimed at improving the sexual and reproductive health of youths. These policies geared towards the improvement of youths' health and life status by influencing future demographic trends and patterns in a desirable direction. Through relevant policies and laws, the government of Uganda recognizes and emphasizes the salience of addressing youth sexual and reproductive health by keeping youths and adolescents in school, improving their sexual and reproductive health and increasing contraceptive use and levels of delivery attended by trained health personnel. These policies include the National Youth Policy,

the National Policy on Young People with HIV and AIDS (Stangl, 2019). A number of other national policies that have beneficial implications for youths' sexual and reproductive health have been put in place in the last four decades: the National Health Policy; National Gender Policy; the Reproductive Health Policy, and National AIDS Control Policy proposals.

Such studies highlight the urgent need to better identify the adolescent and youth-specific barriers to HIV treatment seeking health services in Uganda. Therefore, we qualitatively explored barriers to HIV treatment-seeking in Uganda among youths (age 18–24 years), from their own perspective, complemented with insight from community members and healthcare providers, in order to better understand what factors especially complicate HIV treatment for these groups.

HIV and AIDS-related stigma is defined by Ferrie et al. (2020) as negative feelings, beliefs and attitudes towards people living with HIV (PLHIV), associated groups and other key populations at high risk of HIV infection e.g. youth between 18-24. Goffman (1963) defines stigma as a powerful and discrediting social label that radically changes the way individuals view themselves and are viewed as persons. HIV stigma is negative attitudes and beliefs about people with HIV. It is the prejudice that comes with labeling an individual as part of a group that is believed to be socially unacceptable. Here are a few examples: Believing that only certain groups of people can get HIV. Discrimination is the immediate process of applying the stigma at a behavioural or community level (Bernays et al., 2017; Mumin et al., 2018). According to Goffman (1963), stigma can be classified as follows: enacted and self stigma. According to the study, behavior is the way someone responds to a situation or stimulus. Youths are people in the age bracket 18-24 years of age. Enacted stigma are actions taken by the person concerned in response to stigma, and actions taken against the people concerned, which are discriminative. Self-stigma is the process whereby people living with HIV impose feelings of difference, inferiority and unworthiness on themselves. It is an attribute, behavior, or reputation which is socially discrediting in a particular way or deep feeling one can have, which makes one feel disrespected or unloved. Goffman's work defined stigma as a "mark" that links a person to undesirable characteristics such as stereotypes in a social relationship (Pantelic, Steinert, et al., 2019).

He further distinguished six dimensions of stigma, including; 1) conceal ability (the extent to which the mark is visible); 2) the course (pattern of change over time usually shown by the mark); 3) disruptiveness (does it block or hamper interaction); 4) aesthetic (extent to which the mark makes the possessor ugly or repellant); 5) circumstances on the origination of the mark and peril (kind of danger posed by the mark and its seriousness) (Jones, 2019; Pantelic et al., 2019). Jones emphasized the influence of these dimensions in social relationships. Logie et al., (2019) conceptualized stigma as a co-occurrence of the following: labeling, stereotyping, separation, status loss and discrimination in the presence of power (Macdonald & Kerali, 2021).

It was conceptualized that stigmatization is a social process that can only be understood in relation to power and denomination (Parker et al., 2020). They have argued that stigma is not a “mark” or “an abstract” on an individual but a social process, part of a complex struggle for power that lies at the heart of social life. In their framework, the above scholars encouraged researchers to go beyond seeing stigma as a “thing” which individuals impose on others. Instead, they should look for it in broader social, cultural, political and economic forces, inherently linked to the production and reproduction of structural inequalities (Logie et al., 2019).

Parker et al., (2020) defined stigmatization as a social construct that significantly discredits an individual in a category of people available to him. The aforementioned author stated that stigma should be seen as a language of relationship (Goffman, 1963). Thus, they indicated that stigma can be in a form of physical deformity or blemish of individual character or transmitted through lineage and contaminate members of a family. His description of this attribute indicated that the possession of it reduces the bearer from a whole to a tainted and discounted being. He further claimed that “normal” people exercise varieties of discrimination that reduce the life chances of the stigmatized.

Goffman further dichotomized the persons with a stigmatizing attribute as discredited or discreditable persons. He defined a discredited person as someone whose difference can be spotted on first contact and discreditable as someone whose difference is noticed on first contact. Following the publication of Goffman’s work on stigma in 1963, a lot of refinements and elaboration to the themes that he had introduced have appeared in a wide range of stigma literature. HIV and AIDS treatment-seeking behaviors, on the other hand, is defined as the different attitudes and perceptions held by individuals towards responding to HIV treatment opportunities available.

Many youths have not fully responded to taking anti-retroviral drugs and miss taking drugs within stipulated times, which increases the risk of contracting other related infections. Furthermore, reports indicate (Burgess et al., 2021; Ludwig et al., 2021) that the number of youths with HIV and AIDS deaths has increased in the recent past, despite the efforts by the Ministry of Health and other support organizations to provide free drugs at health centers. This trend has negative impacts on the productivity levels of the youths, thus undermining national development agendas (Arumugam et al., 2020). Several factors might have been responsible for this low response rate of HIV treatment-seeking behaviors, but this current study has contributed to stigma within the study area.

The beliefs that surround HIV infection include, among others, the transmission and origins of the virus which may contribute to this stigmatizing process. Available literature has shown that persons believed to have HIV or AIDS suffer blame and social exclusion. Merging the types and dimensions of stigma as described by Prinsloo et al., (2017), there is a suggestion that people living with HIV and AIDS, especially the youth, are challenged by stigma. The reasons are: 1) their illness is associated with deviant behavior. 2) the infection is seen as a responsibility of an individual for contracting the virus; 3) since the disease is contagious, people consider it as a threat to the community; 4) it is associated with undesirable death and above all; 5) it is not well understood by some religious groups and lay community (Ofori-Atta et al., 2018). The exploration of stigma in this study is, therefore, guided by a combination of bits and pieces of the presented theoretical frameworks underpinning the socio-cultural factors that link stigma and stigmatization.

## **1.2 Statement of the problem**

HIV and AIDS remains a big problem in Uganda. Stigma is identified as a key barrier to prevention and treatment of HIV and AIDS. Failure to treat HIV and AIDS increases the risk of opportunistic infections, reduces life expectancy and increases the burden of care. Evidence on how non-disclosure of HIV status affects the youth 18-24 is limited. Stigma has come to be conceptualized as almost anything people say or do that stands in the way of rational responses to seek health services on HIV and AIDS, or that restricts the access of people living with HIV and AIDS to treatment, care, testing and a reasonable quality of life. Despite the fact that access to treatment for youth living with HIV has been linked to advances in care and awareness campaigns, increased uptake of HIV prevention and treatment services and a general improvement in the wellbeing,

evidence shows that youth living with HIV and AIDS encounter significant factors affecting treatment and care (Li et al., 2017). Youth are among the groups with rising new infections (4.2% girls and 1.6% boys)

Fear that their status will be exposed to others, especially to their fellow peers, continues to be a barrier for those seeking care because some members of the society have inaccurate information about how HIV is transmitted. This creates irrational behavior and mis-perceptions of personal risks; some people think HIV infection is a result of personal irresponsibility (Demirtaş-Madran, 2020). For example, they think the person living with HIV did not mind about him/herself, and still some think that the youth are associated with behaviors such as drug addiction and prostitution. This form of discrimination results in stigma.

However, the research on how HIV medication side effects, and non-disclosure affect treatment-seeking behavior for youth is not adequate. This limits interventions targeting the youth in most developing economies including Uganda. In Uganda, despite high HIV prevalence among young people, there is no stigma index study at the national level and those that have been undertaken were done in Karamoja, Busoga and among sex workers (Looker et al., 2017). However, the focus is on Kampala, with the highest number of youths facing high-risk behavior, given its metropolitan nature. The study, therefore, explored HIV-related stigma effects as perceived by the youths living with HIV and AIDS, and how this affects their behavior in seeking prevention and care services for HIV and AIDS in Kampala city.

### **1.3 Purpose of the study**

The study sought to investigate how stigma influences the treatment-seeking behavior of youth living with HIV in the age bracket of 18 - 24 years old. The study also aims to provide participant-driven views on how stigma among the youth be combated.

#### **1.3.1 Specific objectives of the study**

The study was guided by the following specific objectives:

1. To understand how the youth perceive and experience HIV and AIDS stigma in Kampala City.
2. To describe the nature of HIV treatment-seeking behavior among the youth living with HIV in Kampala City.

3. To examine the role HIV stigma plays in influencing HIV treatment-seeking behavior among the youths in Kampala City.
4. To assess the responses and coping mechanisms of HIV-stigmatized youth in Kampala City.

### **1.3.2 Research questions**

In order to achieve the main purpose and objectives of this study as highlighted above, the research questions include:

1. In what ways do the youth in Kampala City perceive HIV and AIDS? What are the various direct and indirect forms of expression of HIV and AIDS-related stigmatization, discrimination and denial in Kampala, and how do these forms vary across different city locations?
2. What is the nature of HIV treatment-seeking behavior among the youth in Kampala City?
3. Does stigma have a role in influencing HIV treatment-seeking behavior among the youth in Kampala City?
4. What are the coping mechanisms adopted by youth experiencing HIV and AIDS stigma in Kampala City?

### **1.4 Significance of the study**

This study aims at creating awareness about human resource development issues given that the youth comprise a sizable proportion of the population - around 30-35 percent, so their health is critical to national development. This is because stigma is a psychosocial issue and its negative impacts and the benefits of preventing it among the youth living with HIV and AIDS in Kampala and how it has proved to be an obstacle to HIV prevention, care and treatment is important. It also provides the concerned parties in the fight against HIV a platform to air their views and find ways on how this problem can be stamped out of society. To social work, this study highlights another problem associated in the struggle against the HIV epidemic to which social workers are key players. In this struggle, social workers are working hand in hand with other professions like medical personnel, media, politicians, and the courts, among others (Kansiime, 2010). Some professions that social workers work with contribute to the problem.



According to the Constitution of Uganda (1995), the human rights of the youths are supposed to be observed and protected. Thus, stigma and discrimination in one way or the other is a human rights violation, and instead of being over looked, it is brought to the round table and a solution found. For this case, social workers have to play the role of advocating for the rights of the youth living with HIV and AIDS. This creates the need for social workers to fight for the rights of the youth of this age group, who seem marginalized in society, and thus promote social justice. This study will not only increase the practical knowledge of social work but also other disciplines such as medicine, psychology, justice/the Judiciary, journalism and many others because many people in those professions are key service providers to people living with HIV.

Whereas numerous studies have examined the disruptive effect of HIV stigma on health-seeking behavior, particularly for developed economies, the effects of stigma are likely to be context-specific, differing among countries and age groups. The findings of this study, apart from contributing to the growing literature that emphasizes youths in the HIV fight can be used to inform the design of interventions to overcome stigma and to improve treatment-seeking behavior and adherence to treatment regimens of the young population. The findings may also help in the understanding of how coping with this stigma as well as with internalized stigma impacts treatment-seeking behavior. Specifically, study findings may provide recommendations on HIV prevention strategies and services for youths in Uganda in addressing stigma in the context of dynamic behavioral, cognitive and physiological factors that are unique to this group. This might be useful in reducing barriers to seeking treatment where patients follow the list of instructions from the physician and adherence where patients choose to follow through with the prescribed treatment making pick ups/refills, making therapeutic drug monitoring, thus contributing to both the epidemic and the quality of life for HIV positive individuals.

These study findings may provide information to the public health officials at local, district, national and international levels that are relevant for policy making in relation to HIV treatment-seeking behavior of young people. For example, the results of the study have important implications for policy formulation to delivery of HIV-related health services for youths with HIV and AIDS. For instance, the outcome of the study could have important implications on helping in the achievement of the national HIV targets as detailed in the NSP 2015/16 – 2019/20. The findings and recommendations might contribute significantly to the national response to AIDS, guide scale

up interventions in areas related to reducing stigma and discrimination that is still high. Overall, this may help the country to reach the 2020 National HIV strategic Plan targets and the global 2030 targets.

### **1.5 Justification of the study**

Stigma complicates the management and treatment of HIV such as reduced test seeking, limits HIV positive individuals' willingness to disclose their infection, and affects the attitudes of providers who deliver HIV-related care (Ekstrand et al., 2020; Zarei et al., 2019). Therefore, the need to understand stigma's precise nature, dimensions and effects on treatment behavior is very important in the development of interventions to facilitate health among people living with the disease (Nyblade et al., 2017; Shade et al., 2021). Whereas studies have attempted to understand stigma, very few studies have used comprehensive frameworks that address the various dimensions of stigma. The study contributes to HIV stigma literature for young people in developing countries.

### **1.6 Scope of the study**

#### **Content scope**

It is presumed that four stigma manifestations might be prevalent among study participants between 18 to 24 years old. These are enacted, vicarious, felt normative and internalized stigma manifestations. The dependent variable is HIV treatment-seeking behavior defined by two major outcomes: seeking health treatment i.e. something that health care providers do for their patients to control a health problem, lessen its symptoms, or clear it up and adherence to medication i.e. "the extent to which a person's behavior, taking medication, following a diet, and/or executing lifestyle changes, corresponds to with agreed recommendations from a health. This study was conducted in Kampala, the capital city of Uganda, where different people live. The diversity caters for different backgrounds like tribes, religions, education levels, and economic levels.

## **Geographically Scope**

The area where study took place was the urban areas where many youth who are working and who go to schools. The study involved the following health facilities: Nsambya HIV and AIDS Clinic in Makindye Division, and Teenage Section, China-Uganda Friendship Hospital Naguru in Nakawa Division, which are the premier ambulatory HIV and AIDS support centers Kampala - Uganda. The two centers provide care to People Living with HIV and AIDS, including the youths living with HIV in the Kampala area. The study targeted youths (male and female) living with HIV and AIDS between 18 and 24 years of age in Kampala.

## **Time Scope**

It covered a period of seven years (2018-2022). This is the time when HIV treatment-seeking behavior among the youth was highly pronounced.

## **1.7 Theoretical framework**

Cognitive therapy is defined as an insight therapy that emphasizes the recognition and changing of negative thoughts and maladaptive beliefs (Dorsey et al., 2020; Vazifekhorani et al., 2018). Cognitive therapy assumes that people have automatic negative thoughts that occur to them without much notice. Automatic thoughts may be described as a stream of thinking that coexists with a more negative flow of thought patterns (Skinner et al., 2020). By continually repeating these automatic negative thoughts, people colour and distort how they perceive and interpret their world and influence how they behave and feel (Atuyambe et al., 2009; C. K. Campbell, 2021b; Gitahi et al., 2020). The basic assumption is: what you think influences how you feel.

In this study, the researcher used the Cognitive Behavioral theory developed by Beck and Skinner (1986) to gain an insight into understanding the perceptions and how stigma is felt. Beck trained in psychoanalytic techniques and used them to treat clients, many of whom were suffering from depression and stigmatization. These are similar to the thoughts expressed by HIV-positive people that the researcher has noticed. What caught Beck's attention was how patients would express a string of negative thoughts almost automatically, without paying much attention. He reasoned that these automatically occurring thoughts had a great impact on the clients' lives, such as by: lowering their self-esteem, encouraging self-blame, encouraging self-criticism.

Cognitive Behavioral therapy assumes that people have automatic negative thoughts that occur to them without much notice. Automatic thoughts may be described as a stream of thinking that coexists with a more negative flow of thought patterns (Beck, 2008). By continually repeating these automatic negative thoughts, people colour and distort how they perceive and interpret our world and influence how they behave and feel. The basic assumption is: what you think effects how you feel (Skinner, 2020). Cognitive therapy is aimed at modifying underlying core beliefs. Core beliefs are the most fundamental level of beliefs; they are global, rigid and over-generalised.

The cognitive approach used as pre- dominant as it recognizes the interaction of an individual's perceptions, within the broader social processes enabling and reinforcing continuums of acceptability for stigmatizing behaviors. Therefore, this research into understanding how stigma effects HIV and AIDS treatment-seeking behavior among the youth living with HIV, the Cognitive Behavioral Theoretical developed by Skinner et al., (2020). This theory assumes that a person's cognition effects behavior and vice versa. Cognition is a thought or a perception, a belief, a feeling, or a point of view. For example, someone who is afraid of embarrassment and believes one will be embarrassed if one goes for HIV testing or treatment, will avoid it, for fear of being embarrassed (Dorsey et al., 2020; Waajid et al., 2021). Jackson-Best, (2018), focusing on stigma, has largely examined the concept in the context of disability and HIV and AIDS; and has used several theoretical constructs (Skinner et al., 2020). Stigma, in this case, is viewed as a cognitive aspect of human behavior.

This study used cognitive behavioral theory because, it has the characteristics that assist HIV positive youth in understanding HIV and AIDS, to change the experience of coping with internalized stigma and discrimination, and to empower the youth living with HIV and AIDS with more adaptive ways of thinking and behaving. It will be crucial in seeking treatment, adherence to treatment and the adaptation of the youth - as well as in understanding their psychological needs. Cognitive behavior theory (CBT) is used to address the internalized stigma, rejection and discrimination that HIV-positive youth experience. In order to change the way patients think and to promote more realistic and adaptive ways of thinking, cognitive and behavioral methods are

used to challenge dysfunctional beliefs (Dow et al., 2020; Williams, et al., 2019; Mueller, 2019; Slavich, 2020; Turan et al., 2016).

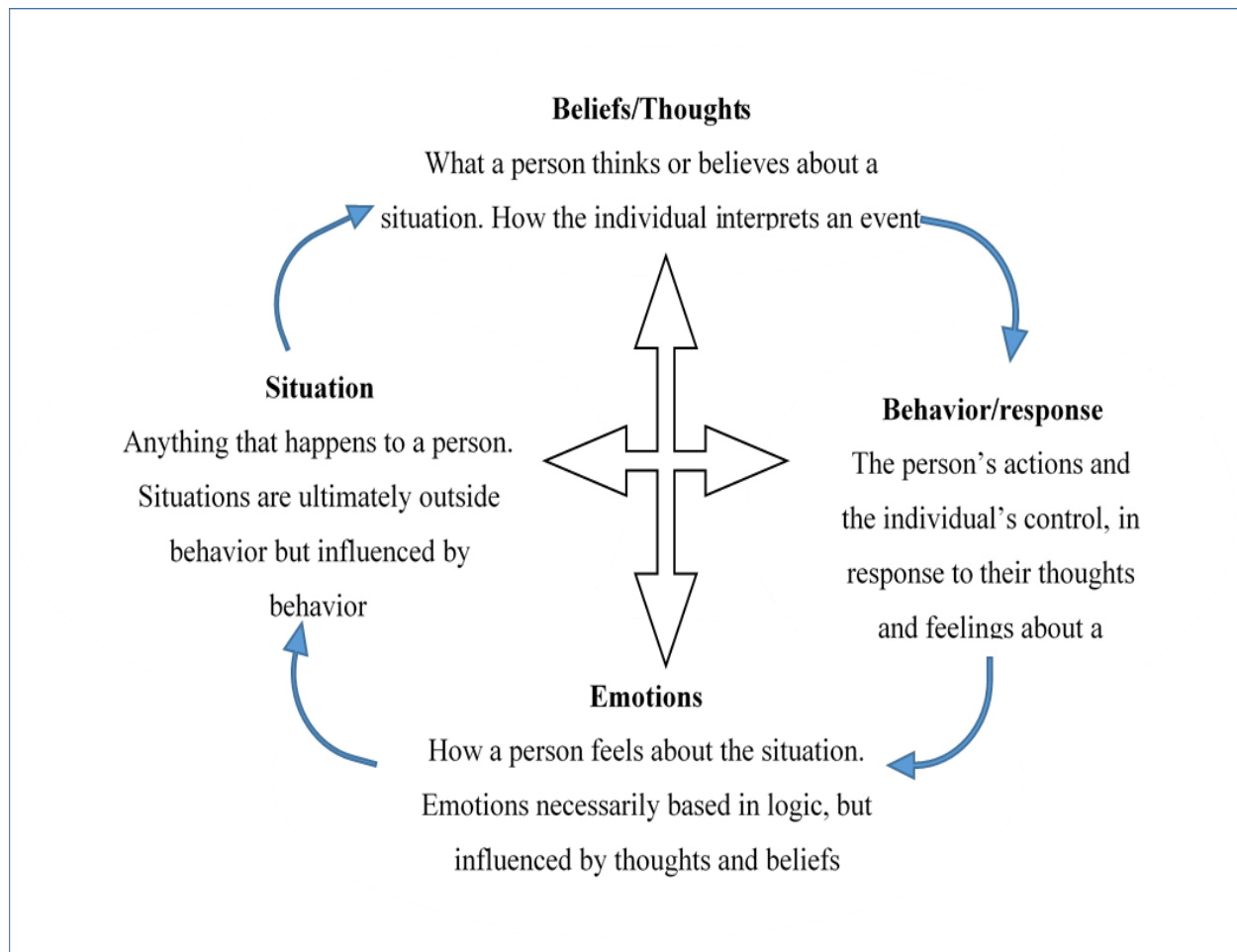
Mukhopadhyay et al., (2020) emphasize cognitive change that can promote behavioral change by allowing the patient to take risks. In turn, experience in applying new behaviors can validate new perspectives. Through both cognitive and behavioral methods, the patient discovers more adaptive ways of thinking and behaving. The theory helps patients to see how unrealistically negative the thoughts are, and therefore persuades them to alter their patterns of thinking (Bavel et al., 2020; Bijl-Brouwer & Malcolm, 2020; Vazifehkhori et al., 2018). HIV-positive youth may, for example, have “irrational” feelings of failure and worthlessness, which can be addressed and modified, according to Layland, (2020) and Feyissa,(2018).

Through this approach, the youth learn how to correct faulty cognitive processing so that it would eventually no longer be necessary to depend on the counselor (Miller et al., 2019; Shinn et al., 2020). Cognitive Behavioral theory maintains that the modification of dysfunctional assumptions leads to effective cognitive, emotional and behavioral change. Cognitive Behavioral Theory is a present-centered, directive, active and problem-oriented approach best suited for cases in which problems can be delineated and cognitive distortions are apparent (Bourdon et al., 2019; Dorsey et al., 2020; Folkman et al., 1986; Shinn et al., 2020; Waajid et al., 2021). The researcher used this approach to develop and assess an intervention model for changing the experience of internalized stigma and discrimination of youth living with HIV and AIDS.

In addition, from this theory, avoidance is the behavior that has resulted from the cognition, which also implies stigmatization. One implication of this cognitive behavioral model is that if cognition is altered, the behavior alters too. This theory expounds that people adapt strategies for dealing with stress. It is further influenced by the assumption that a given situation is controllable or changeable (Bourdon et al., 2019). Therefore, to deal with the stress of a given situation, adaptive strategies are developed to match the situation, including the individual’s conviction and attitudes to reality.

The person facing a stressful situation sees a fundamental component of the coping process as an appraisal. This involves an evaluation of both the demands of the situation and the personal efforts the person can exert to deal with the situation. This theory is chosen by the researchers as a tool or

lens to help in understanding the way participants deal with the situation (Bourdon et al., 2019). It is argued that self-enacted or perceived stigma is a reality that exists as a deterrent to overcoming the HIV and AIDS epidemic. The obtaining of treatment is therefore, a goal for the individual's wellbeing. Figure 1.1 below, shows the Cognitive Behavioral Theoretical framework



**Figure 1-1: An illustration of the cognitive behavioral theory**

The Cognitive Behavioral Theory helps describe how a person's thoughts and feelings interact, and eventually result in a behavior. CBT requires that clients have a strong understanding of the model that the theory is based upon, and the use of this visual guide will help you achieve that goal. In line with Cognitive Behavioral Theory, it is theorized in this study that youths' cognitions about stigma attached to HIV and AIDS treatment greatly determine the extent to which they would seek HIV and AIDS treatment-seeking behaviors. Negative cognitions about stigma attached to HIV treatment would imply that they would not seek this treatment and positive

behaviors would mean that the stigma that people hold about HIV seeking treatment is eroded from youths.

The cognitive behavioral theory (CBT) continues to evolve from its roots in behavior therapy, and it is often represented in summaries of empirically supported interventions. Since the emergence of behavior theory in the late 1950s and early 1960s, cognitive and behavioral theories have merged to produce a theoretically complex combination of therapeutic approaches known today as CBT, though some have continued to debate the merits of adding cognitive components to the traditional behavioral model (Herber et al., 2019; Raj et al., 2018). After a period of development focusing primarily on adult psychopathology, recent years have witnessed the emergence of a wide range of CBT interventions and related research for adolescents and youths.

Dow et al., (2020) and Vazifekhorani et al., (2018) argue that CBT interventions for youths are characterized by the following assumptions: “(a) cognitive activity affects behavior; (b) cognitive activity may be monitored and altered and (c) behavior change may be achieved through cognitive change”. One important facet of cognitive- behavioral theory is the assumption that “cognitive activity” and “behavior” are fundamentally different. Indeed, several authors have regarded cognitive activity as a subcategory of behavior (Haberer et al., 2017a). There are other key propositions within the cognitive - behavioral framework, namely, the environment, overt behavior, behavior, and covert behavior all influence each other. Demirtaş-Madran, (2020) regards the cognitive-behavioral framework as placing “greatest emphasis on the learning process and the influence of the models in the social environment, while underscoring the centrality of the individual’s mediating/information processing style and emotional experiencing”. This definition includes all key components, including (a) learning from direct experience, (b) social learning, and (c) cognitive and emotional mediation.

This study chose to adopt Beck and Skinner theory to analyze how the stigma effects HIV and AIDS treatment seeking among the youth. The theory was used as a logical framework to discuss the effects applied to analyze the formal structures that facilitate or hinder the youth from seeking health services and care.

Both Bourdon et al., (2019) and Waajid et al., (2021) emphasize the meditational strategies. That is, in addition to environmental effects a person’s thoughts and feelings are believed to make a unique contribution to behavioral health (Bonnell et al., 2021; Dorsey et al., 2020; Vazifekhorani

et al., 2018). Kennedy et al., (2019), for example, distinguish between theory and technique by describing theory as “statements that have broad applicability” and technique as the “practical details” of therapy. The value of a well-developed theory is the ability to adapt techniques to new problems, develop new techniques, and add coherence to applied psychology (Abdulai et al., 2021; Silván-Ferrero et al., 2021). Interestingly, most of the techniques used in CBT were derived from either behavioral theories or cognitive theories but not a unified “cognitive-behavioral” theory, and many have argued for a more flexible approach to case conceptualization that incorporates elements of many theoretical perspectives (Dorsey et al., 2020; Miller et al., 2019).

The chief strength of this theory lies in the fact that it not only helps the individual to overcome the symptoms of issues currently being experienced, but also equips the youth with new skills and strategies which can be used with future difficulties or issues (Gombe et al., 2020; Manjate et al., 2020). In addition, the theory focuses on the individual’s thoughts because psychological disorders in many people are found to display maladaptive assumptions and thoughts. The Cognitive Behavioral Theory helps in testing and measuring where theories and methods used in CBT are tested. Furthermore, the theory addresses the root of the problem since the thoughts of a person are the reason for both accomplishments and problems, especially behavior problems. It is also evidence-based, as it has proven efficient for the curtailment of depression and anxiety related issues. CBT is viewed as a cost-effective approach, because it tends to result in change occurring quickly when used with some types of problems.

At the same time, there are some limitations with cognitive behavioral theory. The cognitive model or theories are very narrow in scope since thoughts are just one part of being human – there are more issues that need to be addressed. CBT is classified as a directive theory that aims to change thoughts and beliefs; however, this is sometimes done in a more forceful way. The researcher used this theory to understand and justify the study, as well as an analytical tool to explain how non – disclosure and low HIV risk perception affect the youth in Kampala. In addition, the theory was used in understanding how the youth perceive and experience stigma.



## 1.8 Layout of the thesis

The subsequent chapters of this thesis are structured in the ensuing order;

**Chapter one** describes the background to the study and comprises the different sections that include the problem statement that gives a clear picture of the need for the study; theoretical foundations; the purpose of the study, the objectives of study, conceptual framework, significance and justification, scope of study explicitly provided to show the study contributions to the scholarship.

**Chapter two** presents a review of literature on the subject and highlights the knowledge gap that the study contributes to; for instance, empirical underpinnings and perspectives under which stigma and its effects on treatment-seeking behavior are highlighted and discussed.

**Chapter three** presents and discusses the research philosophy adopted by the study, including the epistemological and ontological assumptions, research design, data collection process such as identification and selection of participants, sampling procedure, study population covered, in-depth interviews, case studies, focus group discussions, and documentary review. Data validity and quality is also presented in this chapter. This was followed by data analysis methods and challenges encountered in the whole process.

**Chapter four** discusses the empirical results about the perception and experiences of youths and collected views from other stakeholders that describe the situation of young people in relation to experiencing stigma and discrimination; the effects of stigma on treatment-seeking behaviors and coping mechanisms in place.

**Chapter five** explores the various barriers to using HIV care services. These include fear of rejection and HIV disclosure, young men and women's lack of support from their families, demanding work schedules, and high transport costs. These highlighted the barriers to seek HIV treatment and care among the youth living with HIV and AIDS in Uganda and more specifically on the nature of stigma of HIV treatment-seeking behavior among youth living HIV in Kampala City.

**Chapter six** focuses critically on discussion on the role of HIV stigma in influencing HIV treatment-seeking behavior among youths in Kampala City.

**Chapter seven** analyses responses and coping mechanisms of HIV stigmatized youth and the identified coping strategies as well as the proposed Stigma Treatment Seeking Behavior Model as a contribution to the existing body of knowledge.

Chapter eight presents a reflection, final discussion and recommendations, addressing stigma; theoretical reflection and implications for the theoretical framework, conclusions, and suggested areas for further study.

### **1.9 Definition of key Concepts**

**Disclosure:** Keeping one's HIV status secret or worrying about others knowing one's HIV status.

**Discrimination:** The act of treating people living with HIV differently than those without HIV.

**Felt stigma:** Feelings of fear and shame stemming from real, potential, or imaginary attitudes or discriminatory acts directed toward an HIV-positive individual and engendered by that individual's HIV status.

**Enacted stigma:** actual past experiences of discrimination, devaluation, and prejudice by others due to one's HIV-positive status.

**Perceived stigma:** Shame, loss of self-efficacy, low self-esteem, low self-confidence and hopelessness associated with HIV stigma combined with side effects from ART, lead to poor

## **CHAPTER TWO: LITERATURE REVIEW**

### **2.0 Introduction**

This section reviews what has been generally documented on stigma and HIV treatment seeking behavior in particular. It further highlights how stigma manifests itself by focusing on the youth, its drivers, the risks faced by youth, their coping mechanisms and contributions on various aspects of HIV-related stigma. It identifies gaps in the available literature with relevance on how non-disclosure and low HIV risk perception affects the treatment-seeking behavior of YLWH and the coping mechanisms in the current study. Gaps in the reviewed literature have been identified and presented in terms of the context, content, time frame, and methodology gaps.

### **2.1 Perception and experience of stigma among PLWH**

At the onset of the HIV and AIDS epidemic, the disease was perceived as deadly and transmissible from person to person. It was closely associated with historically disenfranchised groups and with cultural and historical taboos such as sexual orientation, drug use, and commercial sex work. These cultural and historical taboos resulted in HIV and AIDS-related stigma (Brown, 2020). Many authors tried to define stigma, but did not identify its impact in the experiences of people living with HIV and AIDS, to address and reduce that stigma.

In the context of stigma, Brown continues by asserting that HIV and AIDS does not stigmatize but people do, and identifies an HIV and AIDS-related typology that identifies stigma as being experienced at both individual and societal levels. At the individual level, stigma is defined as those behaviors, thoughts, and feelings that express prejudice against people living with HIV or AIDS (Abrams et al., 2021; Lazarus et al., 2021). At the societal level, AIDS stigma is manifested in laws, policies, popular discourse, and the social conditions of persons living with HIV and AIDS and those at risk of infection. By implication, she and others have identified HIV and AIDS itself as resulting from the socially discrediting attribute (Goffman, 1963). Such attributes have connected the “discrediting” nature of the HIV and AIDS infection to its relationship to historical and cultural taboos such as sexuality and illness, and to ostracized groups (Waldron et al., 2021). The current study tries to connect and bridge the gaps between implications and effects of stigma.

The National Centre in HIV Social Research in Australia (NCHSR) describes the concept of stigma in terms similar to those of Goffman. The process of perceiving a characteristic of another

as being deviant from the social expectations that are held by the two violates social norms, according to Australian Society for HIV medicine (Wright et al., 2018). According to the NCHSR, people living with HIV (PLHIV) experience stigma and discrimination for several reasons. Stigma arises in various spheres of life, including relationships with other people, feelings people have about themselves, throughout different interactions people might have with the broader community. This could include the workplace or health services. Stigmatized people are labeled as different and structures are put in place to protect the two from whatever negative attributes they are believed to possess (Campbell, 2021).

Some literature has sought to identify and describe approaches that may help to overcome stigma. One of the interventions identified as constructive in the fight against HIV and AIDS is to come up with modalities to combat stigma. The role of combating stigma is “giving HIV and AIDS a human face” (Doyal, 2009; Mbonu et al., 2009; Mukhopadhyay et al., 2020). Many efforts include PLWHA in prevention and intervention efforts. However, through this process, PLWHA who are active in public HIV and AIDS programs may have to cope with additional problems associated with being “seen”; just as they are working to overcome public stigma. They may be exposed to more stigma because of their visibility (Wachinger et al., 2021). Since literature provides no remedy, it is in line with this study strived to bridge.

A UNAIDS summary of literature on HIV-related stigma and discrimination recognizes that strengthening of networks of PLWHA, (sometimes called “networks of positives”), can take the lead in addressing stigma (Wachinger et al., 2021). The report also calls for more studies to evaluate anti-stigma and anti-discrimination programs (Wachinger et al., 2021). Moreover, experiences of PLWHA who are members of an existing network will help in forming future HIV and AIDS policies that can be used throughout society and by health care institutions (Stockton, 2018; Nyblade et al., 2017). It is noted that this approach integrates the individual and the societal arenas where stigma is addressed. It provides self-esteem opportunities through which participants may overcome potential internalization of stigma, and social “normalizing” of the stigmatized individuals (Kiwanuka et al., 2021; Vambe et al., 2021; Waldron et al., 2021). This can both be for their own benefit as well as being one among efforts to alter the attitudes of people that designate YLWHA as “other”. The details of the “other” were not well defined.

Meanley et al., (2019) developed a theory to organize and integrate what we know about how stigmatized people react to stigma-related stress. They used stress and coping research findings to predict what effects different stigma-related stress responses are likely to have. Their analysis highlighted some stigma-related stress responses that have thus far received little attention. Although the (Meanley et al., 2019) model is a useful way to organize different responses to stigma-related stress, it is important to remember that stress responses are dynamic, multifaceted and interdependent. People usually make several responses to stress, some of which are coping responses with others being involuntary, emotional, cognitive or behavioral responses (Huang et al., 2021), which may or may not be constructive. This way of thinking about response to the stress of stigma is pertinent to the present study, from the perspective of individual coping strategies.

Stigma research has also given considerable attention to a variety of ways in which stigmatized people may use disengagement from the stress resulting from stigma as a coping method (Green et al., 2016; Hagey et al., 2015; Kalichman et al., 2020; Kiwanuka et al., 2021; Logie et al., 2018; Pellowski, 2013). The two main forms of coping strategies through disengagement that have been studied are physical and social avoidance of situations in which stigma may be a problem (Cuadros et al., 2017; Feyissa et al., 2019; Kirchherr & Charles, 2018; Richterman & Sax, 2020; Rushing, 2018), and denial or minimization of prejudice and discrimination (Gachanja et al., 2018; Kharsany & Karim, 2016; Srithanaviboonchai et al., 2017). Research on general stress reactions suggests that certain types of responses to stigma-related stressors may be maladaptive; in particular those that sometimes lead to depression and psychological distress; maladaptive coping responses would also include disengagement in treatment (Demirtaş-Madran, 2020; Ruria, 2017; Ekstrand et al., 2020; Ensor et al., 2019; Haberer et al., 2017; Yigit et al., 2020).

To understand how stigma works, one needs to be cognizant of what is at stake for both people challenged by stigma and by people who perpetuate stigma, namely the loss or gain of social status, life chances and good fortune. Yang and associates use the term moral experience to collectively define what is at stake in a given social world (Dytone Wella, 2015; Erena et al., 2019; Miller et al., 2019; Russell et al., 2016). Stigmatizing conditions threaten those issues that matter most to the sufferers and non-sufferers: their health, social status and wellbeing, or moral experience. They prompt non-sufferers to respond to the stigma by protecting themselves from the perceived threat posed by the individuals with the stigmatized condition (Stangl, 2019; Stutterheim & Ratcliffe,

2021). Despite widespread findings, claims, and apparent understanding of the logic that stigma serves as a deterrent to overcome the HIV and AIDS epidemic, few studies have addressed stigma among youths, aged 18 to 24, living with HIV and AIDS. Examination of the indicative examples suggests that in seeking to fill this gap, such research must seek the perceptions of the affected individuals. The literature never provided theoretical response to protecting the stigmatized populations

Stigma has created a negative perception of people infected by HIV and AIDS, undermining efforts to reduce the prevalence and spread of the disease (Ekstrand et al., 2020). Monjok et al., (2009) observe that the term stigma has been defined differently by various scholars (Burgess et al., 2021; Birdthistle, 2018; Logie et al., 2018; Maulide et al., 2021). For instance, Goffman defined stigma as “an undesirable or discrediting attribute that an individual possesses, thus reducing that individual’s status in the eyes of society”. Goffman, 1963, as quoted by Radusky et al., (2021) refers to it as “an attribute that links a person to undesirable characteristics” (pg.4). Brener et al., (2021), and argues that “stigmatized individuals are believed to possess some attributes or characteristics that convey a social identity that is devalued in a particular social context” (Martin et al., 2020). Other scholars define stigma as societal processes that are linked to societal power structures. For example, Feinstein (2018); Rueda (2016); Earnshaw (2019); Mak (2017) observe that stigmatization can lead to prejudicial thoughts, behaviors, and actions on the part of governments, communities, employers, health care providers, coworkers, friends, and families.

In his emphasis on the “spoiled identity” and “discrediting attribute” of the stigmatized person has nonetheless shaped the analysis of stigma in predominantly individualistic terms, as mentioned above (Stangl, 2019; Quinn, 2017; Muessig, 2018; Newcomb, 2017; Rimawati et al., 2021). This individualistic framework is influenced largely by social psychology e.g. (Abdulai et al., 2021; Demirtaş-Madran, 2020; Paredes et al., 2021; Slavich, 2020; Teixeira da Silva et al., 2019). These scholars view stigma as an attribute of persons and emphasize the perceptions and stereotypes held by some individuals and the impact of their stereotypical stigmatizing behaviors on the stigmatized persons. In so doing, the individualistic framework tends to ignore the social structural conditions that produce stigma, and instead, constructs stigma as “something in the person stigmatized, rather than as a designation that others attach to that individual” (Bracke et al., 2019; Chory et al., 2021;

Hussain et al., 2021; Pantelic, Sprague, et al., 2019). The framework did not come up with tangible trends to handle such forms of stigma identified.

One aspect of stigma has been defined as a form of exclusion or restriction of expression; marginalization, or prevention from access to something or service (Kalichman et al., 2021). On the other hand, there are those who classify it as “felt or perceived” vs. “enacted” (Bonnell et al., 2021; Derry et al., 2021; Huang et al., 2021; Partow et al., 2021; Reis et al., 2021). Others identify stigma as simply operating within three basic levels: personal, community and institutional. The UNAIDS has, on the other hand, defined HIV-related stigma and discrimination as “... a ‘process of devaluation’ of people either living or associated with HIV and AIDS. Discrimination follows stigma and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status”(Jones et al., 2021). In all these definitions, HIV and AIDS stigma relates to the negative attitudes and perception towards HIV-positive individuals.

People living with HIV and AIDS (PLWHA) face not only medical problems but also social problems associated with the disease. The reaction to people living with HIV and AIDS (PLWHA) varies. Some PLHWA do receive support and care in constructive and non-stigmatized ways. HIV and AIDS stigma is widespread and has been found to negatively affect HIV test seeking, seeking care after diagnosis, quality of care given to HIV patients and, finally, the negative perception and treatment of PLHWA by their communities and families, including partners (Nakanwagi et al., 2016; Nosyk et al., 2014; Ortblad et al., 2017). However their findings did not come up with models like the current study has done.

## **2.2 Perception and experience of HIV and AIDS stigma by youth**

Perceived stigma and social support are correlated with the QOL in PLWH (Camlin et al., 2017b, 2020; Kennedy et al., 2020; Pantelic, 2019). Mukhopadhyay et al. (2020) studied youth living with HIV and AIDS in secondary schools, giving perspectives of peer educators and patron teachers in western Uganda, with the use of qualitative approaches, empirically established that getting infected or being disclosed to, the sero-positive status is a stressful and emotionally traumatic event to the youth. Further, in this study, it is ascertained that HIV and AIDS is historically associated with death and is highly stigmatized. However, this reviewed study did not use theories like the ones the current study is adopting.

Similarly, Gachanja, Burkholder and Ferraro (2018); Mukhopadhyay et al. (2020) studied disclosure within HIV-affected families and found out that many children and youths fear disclosure of HIV due to stigma associated with HIV and AIDS infections. Further, the reason for youth non-disclosure is fear of losing partners or partners leaving relationships. This study was carried out in a developed world context in the USA, while the current study was carried out in Uganda, a developing world. Theoretically, Odimegwu et al. (2017) researched about HIV stigma in Nigeria and in a review established that discrimination results from stigma when any form of distinction, exclusion or restriction is displayed against an individual because of an attribute or personal characteristic.

Available reports have indicated that within Kampala Capital City Authority, youths with HIV and AIDS have neglected HIV treatments offered. Many have not fully responded to taking antiretroviral drugs, miss taking drugs within stipulated times, which increases the risk of contracting other related infections. Furthermore, reports indicate (Burgess et al., 2021; Ludwig et al., 2021) that the number of youths with HIV and AIDS deaths has increased in the recent past, despite the efforts by the Ministry of Health and other support organizations to provide free drugs at health centers. This trend is impacting negatively on the productivity levels of the youth, undermining national development agendas (Arumugam et al., 2020). Several factors might have been responsible for this low response rate of HIV treatment-seeking behaviors, but the contribution of stigma was not exposed, which this current study did.

### **2.3 The nature of HIV treatment seeking behavior**

The empirical evidence on the nature of HIV treatment-seeking behavior has been growing. Numerous studies have reached conclusions that HIV stigma among people living with HIV complicates treatment-seeking behavior across many countries, both developed and developing nations (King et al., 2021). However, to understand the treatment-seeking behavior linkage with HIV stigma, it is imperative to understand the different health services PLHIV need. One of the health services PLHIV needs is Voluntary Counseling and Testing (VCT) services. VCT plays a pivotal role in HIV prevention, treatment and care, early diagnosis of HIV infection as well as timely therapeutic or prophylactic interventions (Erena et al., 2019; Liu et al., 2018; Vazifehkhori et al., 2018). In this literature, there was no theoretical approach to confront this problem.



HIV testing and counseling has further been shown to promote risk reduction in certain groups, behavior change and reduced transmission. It assists HIV-positive individuals in accessing intervention and support services, including management of other infectious diseases, education about living with HIV and avoiding infection of others. VCT also assists uninfected individuals in assessing their personal risk and adopting risk reduction behaviors, as well as strengthening prevention efforts, particularly at the community level (Meanley et al., 2019). Factors positively related to HIV testing in the Republic of South Africa include older age, greater education, greater HIV knowledge, higher risk perception, and knowing someone with HIV (Derose et al., 2017). The actual uptake in most of sub-Saharan Africa remains quite low, despite the utility of VCT (Nasuuna et al., 2021; Omotoso, 2021). It is estimated that only about 45% of people living with HIV in sub-Saharan Africa know their status (Tattsbridge et al., 2020; Zhang et al., 2016).

There are significant barriers to engaging youths living with HIV and AIDS in HIV-related care, which greatly predicts clinical success, including treatment adherence and viro-logical suppression (Kirchherr & Charles, 2018). Many young people do not access health services because of perceived barriers related to the availability, accessibility, appropriateness and relevance of health services (Lauterbach, 2018). For adolescents and youths who live in rural areas, accessing sexual health information, testing, and medication can be challenging (Ogunbajo et al., 2017). In other instances, healthcare centers may not offer the necessary services (e.g., family planning options). In under-serviced areas, healthcare centers may not offer comprehensive or more specialized services required by adolescents and youths (Swann, 2018). They may have to travel to neighboring towns or cities to access appropriate care, which can be time-consuming, expensive, and can threaten disclosure and confidentiality. No solution was provided or put in place to help the youth in accessing services at ease.

Parental consent for sexual health-related procedures and medications is an important limitation as mandatory parental consent for sexual health tends to reduce adolescents' willingness to access them (Choko et al., 2018; Ensor et al., 2019). Talking with youths, living with HIV and AIDS about their sexual health can be difficult, and compassion and patience is required from health care providers. This ensures the individual that they are in a safe, secure, and accepting environment. Unfortunately, many adolescents below 18 years old and youths living with HIV and AIDS experience judgmental health care environments and hostile health care workers (Haberer et al.,

2017a). Youths living with HIV and AIDS have long voiced their frustration with the lack of youth-friendly messaging and language that would enable them to feel more comfortable and accepted (Xu et al., 2017).

Experiences of healthcare workers being critical and disapproving of their lifestyle may inhibit the likelihood for an individual to discuss sensitive topics such as STI testing in future (Nakanwagi et al., 2016; Ortblad et al., 2017; Twikirize & Spitzer, 2019). Adolescent and youth, who are street-involved or involved in drug use, report feeling stigmatized and discriminated against by health providers, which often prevents them from asking questions about their health or returning for follow up (Hayes et al., 2019). Given that young people represent one of the fastest-growing HIV-affected populations, it is imperative that healthcare and prevention services meet the needs of this unique population. The analyses in this dissertation will provide evidence to support the demand for improved health services for youths living with HIV and AIDS.

In a study of predictors of HIV-related stigma among youths living with HIV, enacted and perceived HIV stigma was examined among substance-using young people living with HIV (YPLH) in Los Angeles, San Francisco, and New York City. Eighty-nine percent of the participants reported perceived stigma and 31% reported enacted stigma experiences in the past three months; 64% reported stigma experiences during their lifetime. The HIV stigma experiences were characterized by factors of avoidance, social rejection, abuse, and shame (Tattsbridge et al., 2020). Findings of the study (Gregson et al., 2017; Iqbal et al., 2019; Jacobi et al., 2020; Omotoso, 2021; Skovdal, 2019; Vyavaharkar et al., 2010; Zhang et al., 2016) also indicated that enacted stigma was associated with gay or bisexual identity, symptomatic HIV or AIDS, and bartering sex.

Perceived stigma, on the other hand, was associated with female gender, symptomatic HIV or AIDS, lower rates of injection drug use, and fewer friends and family knowing sero-status. Gay or bisexual youths who were also HIV symptomatic or AIDS diagnosed experienced more HIV stigma than their heterosexual peers did. The findings are, however, silent about stigma among youths living with HIV and AIDS, a gap the current study seeks to fill. Both authors have suggested that service providers can help to address the impact of stigma as a deterrent to treatment seeking and adherence to medical regimens for this group. Providers can offer guidance in the disclosure process, supporting youth in the problem-solving process, and encouraging them to consider the positive aspects of disclosure, such as access to social support, access to highly affective

medication, and reduced stress (Bourne et al., 2017; Dubov et al., 2018; Thomas et al., 2019). The literature did not indicate the guidance provided to support the youth as this study did.

Perceived HIV-related stigma often impairs social relationships among young people. However, the effect of social support and the process by which it affects the relationship between HIV-related stigma, coping and health outcomes is not clear (Nasuuna et al., 2021). Even though the need for social support might vary from person to person and from time to time, it is considered essential for adequate personal adjustment (Chan & Tsai, 2017). Absence of social support leads to distress. Although many studies reported on social support and its effect on the lives of people living with HIV and AIDS, there still is a limited understanding of the mechanisms and processes through which it may exert its effect among youths living with HIV and AIDS (X. Yang et al., 2020). Researchers found that the Western concept of emotional support is unfamiliar to African people living with HIV and AIDS. As a frustrated participant who had been in and out of care was quoted, “All we do is eat, talk, and light candle!” (Derry et al., 2021; Huanget al., 2021; Partow et al., 2021; Wachinger et al., 2021). In a recent study among 259 adult HIV-infected immigrants in Canada, of whom 70% were black, participants reported that perceived social support has a significant negative relationship with depressive symptom (Herd et al., 2019; Liu et al., 2018; Shingleton & Palfai, 2016). This study bridged the gap in the need for understanding youths’ perspectives.

Furthermore, Bracke et al., (2019) assert that studies do not account for the broad array of the source, types and functions of social support. Assessing social support from multiple sources in the social network is critical in the understanding of its impact in populations like youths living with HIV and AIDS. As individuals born in rural areas acculturate and create several social interactions within their own local communities as well as to the hosting communities, their perceived level of social support may vary across distinct groups with which they interact. Thus, youths living with HIV and AIDS fear being stigmatized and losing their social support if their HIV status becomes known: HIV rates may be higher in the context of their own respective communities than the general community, if the stigma attached to HIV infection is higher in their local communities of their own origin (Bracke et al., 2019; Zimmerman, 2015).

According to Bonnington et al., (2017), barriers to seeking health services for young people include availability and acceptability of services, including waiting time, costs and pressure by

health staff to notify partners; worries about confidentiality and fears that results would be shared with parent(s) or partner(s). Inaccurate risk perception, fear of being labeled and stigmatized by their families, friends and communities' perceptions of the consequences of living with HIV, inadequate responses from healthcare providers, including counselors, to effectively meet the HIV prevention, care and support needs proper attention of youth (H. Liu et al., 2018). Bonnington's study in Southern India concluded that stigma complicates the treatment of HIV worldwide. Using qualitative interviews with a convenience sample of 16 people living with HIV revealed all three types of stigma; enacted stigma, felt normative stigma and vicarious stigma. The findings suggested that experienced stigma was associated with higher levels of depression (Rudolph et al., 2021). The findings revealed the forms of stigma but did not report the coping mechanisms as this study has done.

Akatukwasa et al., (2021) and Bonnington et al., (2017) examined whether the four stigma manifestations-enacted (discrimination), vicarious (hearing stories of discrimination), felt normative (perceptions of stigma's prevalence), and internalized (personal endorsement of stigma beliefs) - were linked with delays in seeking care among HIV-infected people in India. They conducted a cross-sectional survey among 961 HIV-positive men and women in Mumbai and Bengaluru. The study outcomes showed that enacted and internalized stigma correlated with delays in seeking care after testing HIV positive. The study concluded that developing stigma reduction interventions is vital to ensuring timely receipt of care (Ensor et al., 2019).

In another qualitative study of HIV-related stigma and discrimination in Iran, Oskouie et al. (2017), argued that HIV-related stigma is a major social problem of people living with HIV and the stigma interferes with the prevention, diagnosis and treatment of HIV particularly for women. In the study examining the experiences of HIV-infected women who were stigmatized, the results showed that HIV-positive women in Iran, greatly faced with embarrassment and isolation, usually do not seek medical care in a scheduled program (Oskouie et al., 2017). The qualitative study on the perception of patients with HIV and AIDS on stigma and discrimination in Iran also revealed that HIV and AIDS stigma and discrimination were multidimensional (Saki et al., 2015). The stigma, rejection, insult and discrimination in receiving health services play an important role in patients' lives and hinder them from accessing the treatment. After finding the roles of stigma in their study there were no remedies provided, but this study suggested some solutions.

In Nigeria, Odimegwu et al.' (2017) review of HIV-Stigma in Nigeria between 1999 and 2016 revealed the prevalence of HIV stigma and its effect on testing, treatment uptake, adherence, care, and support. The review showed that a meta-analysis of 64 studies conducted in different settings demonstrated significant effects of HIV-stigma on mental health, quality of life, use of health services, and physical health of PLHIV (Odimegwu et al., 2017). They noted that the manifestations or expression of stigma translates into different forms of inequalities in access to HIV care, treatment, and support. The Meta - analysis did not demonstrate how the significant effects of stigma could be handled but the current study did.

The study into the manifestation of stigma and discrimination and its consequences on HIV and AIDS prevention and treatment efforts amongst people living with HIV and AIDS revealed that stigma and discrimination undermine HIV treatment, delayed testing and disclosure and reduced quality of care (Arumugam et al., 2020; Zha et al., 2021). They noted that in Masvingo, fear of rejection had led people to grind drugs into powder that can result in inconsistent doses. The prevalence of stigma and discrimination is a barrier to effective HIV treatment programs because it results in the low uptake of and poor adherence to treatment services. In relation to delayed testing and disclosure, it was found out that stigma and discrimination causes delayed testing and prevents disclosure of an HIV positive status to partners, providers and family members (Bórquez, 2020; Rebhook, 2017).

Dow et al.' (2020) study among people living with HIV and AIDS in resource-limited settings in Ethiopia suggest that the experience of stigma and discrimination has an implication on care and support-seeking behavior. Findings also showed that the messages that were initially disseminated through mass media (e.g., radio and television) combined with limited effort to raise awareness within the community about the disease were identified as factors that affect the current level of stigma and discrimination.

HIV and AIDS-related stigma was found to influence seeking of voluntary counseling and testing. In a study conducted in South Africa, stigmatizing beliefs about AIDS and their associated fears of discrimination can influence decisions to seek HIV testing and treatment services (Bonnington et al., 2017a; Makhema et al., 2019a, 2019b). Another study carried out by Rushing (2018) found that health-seeking behavior of the youth with regard to voluntary counseling and testing was low mainly because of different kinds of fear. This is similar to a survey done among urban youth in

Kampala, Uganda. This revealed that only 9% were involved in HIV health activities, although 81% of youth 18-24 had ever heard of VCT (Kimera et al., 2019).

This was due to being scared of results, fear of psychological effects and stigma, which is in agreement with a study carried out in South Africa that indicated only one in five people who know about VCT tested for HIV. However, the reasons that South Africans gave for not seeking HIV testing were negative perceptions of testing services (Dubov et al., 2018; Haberer et al., 2017). In South Sudan, Machine et al. (2011) in a study among health workers at a local hospital, a women's group, local market traders, religious leaders, and teachers, found out that stigma persisted. Not only toward people with conspicuous signs of full-blown AIDS, but also towards community programs like voluntary counseling and testing centers (Wamoyi, 2020; Rosenberg, 2019; Poteat et al., 2021).

Nonetheless, (Kalichman, 2017) observed that people living with HIV and AIDS (PLWHA) are stigmatized and looked at negatively by people at large. However, the stigma, discrimination, and prejudice also arise from people such as health providers, hospital staff, as well as family members and friends. Kalichman, (2017) argues that studies demonstrate that in low-income countries, especially in South Asia and sub-Saharan Africa, health providers' views toward the HIV-positive individuals are not very much different from the general population. Therefore, using the qualitative research approach, the study interviewed health providers (physicians and nurses) attached to different hospitals in Bangladesh. The findings showed that 80% of the nurses and 90% of the physicians' behavior towards HIV-positive individuals was discriminatory and, therefore, the fear of discrimination often prevents people from seeking treatment publicly (Camlin et al., 2017; Nakanwagi et al., 2016). The current study used qualitative approach to identify solutions towards youth who were affected stigma and discrimination.

## **2.4 Stigma and HIV treatment-seeking behavior**

Consequences of stigma can be viewed along a continuum from mild reactions (e.g. silence and denial), to ostracism and, ultimately, violence (Kooij et al., 2021; Reif et al., 2021; Van Der Kooij et al., 2021). Stigma has consequences that are clustered into social, psychological and health problems. The social consequences include the disruption of relationships, hampering of the development of new relationships, reduction in social networks, and isolation. Psychological consequences include anxiety, depression and lowered self-esteem. Consequences in the health

arena include limiting the number of social service and medical providers and delays in treatment and testing (Kroidl, et al., 2019).

A large body of literature exists on the impact of HIV-related stigma on psychological and physical health of PLHA. Among the most common of these impacts are increased feelings of despair (Chemhaka et al., 2021; Pollini et al., 2021; Surratt et al., 2021); increased rates of depression (Earnshaw et al., 2020; Pearson et al., 2021); decreased self-esteem (Kutner et al., 2021); and increased mental health issues in general. From the early days of the epidemic, layers of stigma have unfortunately helped to extend and deepen the AIDS stigma experienced by many with HIV (Abdulai et al., 2021; Satyanarayana et al., 2021; Seffren et al., 2018; Turan et al., 2017; Turan et al., 2019; Wilson et al., 2019). Layers refer to the reality that PLWHA are often challenged by stigma, both for this condition and for other aspects of who they are: members of racial and gender minorities, impoverished, participants in stigmatized activities such as drug abuse and sex work. Each layer works in interaction with the others, both as enacted stigma and as self-stigmatization (Pearson et al., 2021; Reif et al., 2021; Van Der Kooij et al., 2021).

Turan, (2019), examined the relationships between HIV-related stigma and a range of demographic, social, physical and health characteristics. It was found that higher levels of stigma were consistently and significantly associated with low social support, poor physical health and poor mental health, and concluded that the association between HIV-related stigma and physical health has potential implications for the treatment, care and support for people at different stages of HIV infection (Batchelder, 2021; Harris, 2018; Mutchler, 2019). HIV-related stigma also affects health directly by complicating HIV treatment adherence. There are situations in which fear of rejection has prevented people living with HIV and AIDS (PLWHA) from taking their antiretroviral medication on time (Obiri-Yeboah et al., 2016; Stutterheim & Ratcliffe, 2021).

The fear, lack of privacy and respect for confidentiality, likely in many settings lead to forced disclosure. Individuals will then, without preparation or choice, be forced to face the results of stigma: prejudice, discrimination, the loss of a job, strains on or the breakup of relationships, social ostracism, or violence (Batchelder, 2021; Batchelder et al., 2021; Harkness et al., 2021). The study concluded that healthcare workers who encourage PLWA to disclose their HIV status must carefully consider the implications of encouraging disclosure in an environment with high levels of stigma, and must recognize the real possibility that PLWA may experience serious verbal and

physical abuse because of disclosure. This may thus have an implication in treatment-seeking behavior (Arumugam et al., 2020; Azia et al., 2016; Ochom et al., 2019; Quinn et al., 2019).

As noted by Stangl and Brewer discrimination adds to the daily struggles faced by people living with HIV and AIDS in Uganda; people who are predominantly poor and disproportionately immigrants. Health service providers have difficulty recognizing how hard it is for their clients to meet basic needs: coping with poverty, hunger, illiteracy, inadequate medical care, inadequate transportation, and homelessness. In addition to those basic needs issues, people with HIV and AIDS face a series of critical civil rights problems. She emphasizes that individuals living with HIV and AIDS need to know their rights and need the resources to advocate for themselves when their rights are threatened. Like others above, the study noted that fear of a breach of confidentiality, (although it is illegal), fear of potential consequences, (social stigma, rejection by loved ones, being evicted from an apartment, losing a job, suffering harassment or violence), may be the result of stigma. This may lead to avoiding testing and treatment (Deering et al., 2021; Li et al., 2017). The study came up with different ways how people stigmatized can get tested without fear.

#### **2.4.1 The nature of HIV treatment-seeking behavior among youths**

Kimera et al. (2019) stressed that ART availability and effectiveness has a life-long capacity to reduce further HIV infections. This kind of treatment is reported as good, as it reduces rashes over the body and consequently, improves the health condition of the affected person. Meanwhile, this study depended only on ART, while the proposed study captured other treatment behaviors in Kampala. Akatukwasa et al., (2021) showed that stigma and discrimination act as impediments to the uptake of HIV testing, treatment, care and adherence to treatment. A consistent, negative association was found between fear of rejection or perceived stigma and use of testing and treatment services. Besides, the nature of HIV treatment-seeking behaviors among youths is not yet empirically established, which the current study will do (Feyissa, 2018a; Lazarus et al., 2021).

In more or less the same way, Nasuuna showed that some youths are suspicious that the interviewing team asks infected youths questions and that the acquired information is offered to local authorities, which has made many not avail the required information. This scenario was disclosed in Zambia, where the situations may differ with what youths are experiencing in Uganda (Culbreth et al., 2019; Kimera, Vindevogel, Rubaihayo, et al., 2019a; Kumar et al., 2020; Swahn



et al., 2019a, 2021). These studies showed that the strategies of taking HIV drugs are at times impossible when it gets to meeting deadlines. At times when these youths are at school, they cannot pack drugs while on another occasion some fear that once they miss swallowing drugs, it may not be safe for some to swallow them. This implies that the scheduling of drug consumption is not at times easy to follow due to tight educational schedules, which normally interfere with preventing conduct problems and drug use on follow up measures (Dorsey et al., 2020; Dow et al., 2020b; Siril et al., 2017a, 2017; Mak, 2017).

#### **2.4.2 Factors that affect young people's uptake of treatment services**

According to Deblonde et al. (2010); Dessalegn et al. (2019; Landefeld et al. (2018a; Ogunbajo et al. (2017), barriers to treatment-seeking services for young people include availability and acceptability of services, including waiting time, costs and pressure by health staff to notify partners, worries about confidentiality and fears that results would be shared with parent(s) or partner(s). Some other factors are inaccurate risk perception. Fear of being labeled and stigmatized by their families, friends and communities' perceptions of the consequences of living with HIV. Furthermore, inadequate responses from health care providers, including counselors, to effectively meet the HIV prevention, care and support needs of youth complicate the situation (Bakeera-Kitaka et al., 2008; Begun et al., 2020; Gombe et al., 2020; Kimera, Vindevogel, De Maeyer, et al., 2019a).

AIDS-related stigma is another factor that probably effects seeking voluntary counseling and testing as indicated by a study done in South Africa. Stigmatizing beliefs about AIDS and their associated fears of discrimination can influence decisions to seek HIV testing and HIV treatment services (Abubakari et al., 2021; Ahn et al., 2019; Li et al., 2017). In a report by International Information Support Center on Implementing HIV, testing for individuals revealed that costs affected whether or not people sought HIV counseling and testing (Akutukwasa et al., 2021; Skovdal, 2019; Thomas et al., 2019). These studies found that barriers to VCT for the young people include costs attached to the services which were similar to a study conducted by Akutukwasa et al. (2021); Dow et al. (2020); Lowenthal (2014); Nyblade et al. (2020); Rudolph et al. (2021); Skovdal (2019); Thomas et al. (2019). In Bushenyi District, it was found that cost and physical accessibility of VCT services was among the factors that influenced acceptability of HIV testing.

A study carried out by Kiwanuka et al. (2021), found that treatment-seeking behavior of youth with regard to voluntary counseling and testing was low mainly because of different kinds of fear. This is similar to a survey done among urban youth in Kampala Uganda, which revealed that only 9% were involved in HIV treatment-seeking activities although 81% of youth 18-24 had ever heard of VCT (Elul et al., 2017; Erena et al., 2019; Kennedy et al., 2020; Makhema et al., 2019a). This was due to being scared of results, fear of psychological effects and stigma that is in agreement with a study carried out in South Africa that indicated only one in five people who know about VCT tested for HIV. However, the reasons that South Africans gave for not seeking HIV testing were negative perceptions of testing services (Anywar et al., 2020; Ogunbajo et al., 2017; Pourjam et al., 2020). This study explored why there is still low HIV treatment-seeking services uptake in Kampala City despite the availability of youth friendly services.

#### **2.4.3 Stigma reduction efforts**

Health promotion programs worldwide have long been premised on the idea that providing knowledge about causes of ill health and choices available will go a long way towards promoting a change in individual behavior (Batchelder, 2021; Logie, 2018; Amirkhanian, 2018). Both of these can reduce enacted stigma and help HIV + individuals and their care providers to be more consistent in their treatment-seeking behavior. The underlying assumption is that knowledge will help to overcome stigma. However, there is growing recognition, in both developed and developing countries, that providing education and knowledge at the individual level is not sufficient in itself to overcome stigma on a broad social scale (Tattsbridge et al., 2020).

Most of the work on stigma reduction identified for this review, concerned stigma associated with mental illness, where stigma is identified as a significant barrier to help seeking. This leads to negative attitudes about mental health treatment and deterring individuals who need services from seeking health care clinics. The social stigma (negative attitudes held by the public) based on racial differences has a bearing in treatment-seeking attitudes and behaviors among youth with depression (Dubov et al., 2018; Kiwanuka et al., 2021; Nasuuna et al., 2021; Zhang et al., 2016). In a study among African Americans, (Mumin et al., 2018; Paintsil et al., 2020) it was found that internalized stigma did mediate public stigma; internalized stigma was directly related to attitudes toward mental health treatment. The internalization of stigma is considered key in the development of negative attitudes toward mental health treatment. They recommended that future research

should focus on this aspect of stigma in both individual and community-based efforts to reduce stigma.

The focus on education of the marginalized and stigmatized groups needs exploration. A study by Mumin et al. (2018); Pearson et al. (2021) did not find support for the hypothesis that individuals exposed to a brief session of mental health education will have more positive attitudes toward seeking psychological services. The findings in Mumin and Pearson's study indicated that although there is a significant relationship between stigmas and attitudes toward seeking help, brief mental health education did not improve these attitudes. An effective strategy of reducing social stigma is to increase interpersonal contact between community members and members of the stigmatized group. It is pertinent that contact between stigmatized and non-stigmatized groups work as a vehicle of stigma reduction (Pearson et al., 2021).

This is most effective when the contact is between people of equal status, (fostering mutual identification), is personal, voluntary and cooperative, and judged a positive experience. These encounters can be marked by such characteristics as breaking down in group/out –group boundaries of “us” and “them” (White, 2016). Reducing social distance and increasing interpersonal contact are important strategies or goals of any anti-stigma campaign. The major long-term goal of the current exploratory study of challenges faced by people living with HIV in Kampala is to inform the adaptation of group risk interventions for the needs of youth living with HIV. Stigma, as a widely accepted hurdle to seeking treatment, is explored with specific reference to the specific population: the youths.

## **2.5 Responses and coping mechanisms to HIV stigma**

Chan & Tsai, (2017) established that widespread availability of treatment has been associated with improved health outcomes, regained self-esteem, improved life expectancy and reduced stigma. Further, antiretroviral therapy could reduce HIV stigma. All four approaches for de-stigmatizing suggested information-based approaches such as brochures, second skills building activities, and hands-on learning strategies that counter negative attitudes. The third approach is counseling and fourth is contact with people living with HIV, especially through testimonials and interaction with the general public (Adeniyi et al., 2018; Chan & Tsai, 2017; Mwamba et al., 2018). However, the current study is evaluating the extent to which these approaches applied to de-stigmatize HIV among youths in Kampala City are undertaken with appropriate approaches.

According to Bórquez (2020); Arinaitwe et al. (2021); Camlin et al. (2017); Seffren et al. (2018), improving the availability and accessibility of health services, training health care workers in primary health care in the diagnosis and management of Sexually Transmitted Diseases, screening for STD in pregnant women, targeting STD prevention and care programs are most effective to reduce HIV infections. In addition, there is stigma related with sexually transmitted diseases. Government of Uganda (2015), showed that due to high risk of HIV and AIDS in the GARPR-reporting period, national survey and surveillance data, several strategies like HIV testing and counseling (HIC) have been put in place. Treatment, prevention, care and support centers, monitoring and evaluation have been adopted; such strategies involved safe medical circumcision (Bonnington et al., 2017; Havlir et al., 2019; Kuhns et al., 2021).

HIV related stigma is particularly harmful to adolescents and youths because of their stage of development (Kalichman et al., 2020; Srithanaviboonchai et al., 2017; Tumwikirize & Zwane, 2016; Woodgate et al., 2017). Young people are in the process of making a multitude of rapid transitions, both physical and social (Srithanaviboonchai et al., 2017). The factors that interfere with their sense of self, such as enacted stigma, have far-reaching effects on overall development (Brown et al., 2021; Brewer, 2020; Rueda, 2016; Shade, Marseille, et al., 2021; Weber & Weber, 2020); Winchester & Macgrath, 2017; Yaghmaian & Johnson, 2016). In a study of predictors of HIV related stigma among youth living with HIV, enacted and perceived HIV stigma were examined among substance-using youth living with HIV (YPLH) in Los Angeles, San Francisco, and New York City. Eighty-nine percent of the participants reported perceived stigma and 31% reported enacted stigma experiences in the past 3 months; 64% reported stigma experiences during their lifetime. The HIV stigma experiences were characterized by factors of avoidance, social rejection, abuse, and shame (Choko et al., 2018; Erena et al., 2019; Friedland, 2020; Gunn et al., 2021; Rahman et al., 2020).

While studies suggest that reducing stigma does increase the individual as well as community acceptance of people living with HIV and AIDS, there is little information available on how this process can be fostered (Bijl-Brouwer & Malcolm, 2020; Jones, 2019; Logie et al., 2020; Logie, Dias, et al., 2019). Related literature on this point will be from the following scholars: Chambers, Rueda, Baker, Wilson, Deutsch, Raeifar, Rourke, Adam, et al. (2015); Delva et al. (2012); Quinn (2017); Lofgren et al. (2021); Manjate et al. (2020); Papageorge (2021); Mak (2017). Literature

on HIV related stigma is growing, but little is known about experiences of specific groups of young persons living with HIV and AIDS.

Behavioral, psychosocial, and environmental factors have contributed to the increased rate of HIV transmission in Sub-Saharan Africa and have played a major role in reducing the quality of life and hastening the premature deaths of PLWHA (Liu et al., 2021). The factors have included, but have not been limited to, discrimination, lack of social support, restricted access to health care services, stigma and discrimination toward PLWHA, gender inequalities, and job insecurity that leads to depression (Ofori-Atta et al., 2018; Turan et al., 2016; Vyavaharkar et al., 2019). Rios et al., (2020) argued that environmental factors such as lack of access to medical equipment and health care also could jeopardize the well - being of PLWHA. Opinions vary on the effectiveness and limitations of behavioral change. The intervention programs in preventing HIV and AIDS and prolonging the lives of all PLWHA; however, what is clear is that behavioral change intervention approaches to HIV prevention and care need to span all societal factors and must be tailored specifically to the drivers of HIV transmission, especially among vulnerable young men and women. Camlin et al. (2017) and Macdonald & Kerali (2021) argued that HIV and AIDS – related stigma and discrimination can have a significant impact on achieving universal access to HIV seeking – treatment, prevention, care, and support programs needed by PLWHA.

Unfavorable social, political, environmental, psychological, and cultural conditions in many communities result in large disparities in the provision of health among population subgroups (Cuadros et al., 2017; Gunn et al., 2021; Becasen, 2018). Consequently, research efforts geared toward ways to reduce or eliminate HIV and AIDS - related stigma and discrimination are needed. These must apply new approaches to explore, identify, and analyze concepts that take into account the social, cultural, political, psychological, and environmental determinants of stigma and discrimination (Akutukwasa et al., 2021; Batchelder, 2020; Batchelder et al., 2021a; Chambers, Rueda, Baker, Wilson, Deutsch, Raeifar, Rourke, & Team, 2015; Partow et al., 2021). Previous research has emphasized the need to explore these processes in the range of contexts to guide the development of programs and interventions to reduce HIV –related stigma and discrimination (Feyissa, 2018; Stockton, 2018; Mumin et al., 2018; Partow et al., 2021).

### **2.5.1 Stigma and power dynamics**

A sociological summary of literature on HIV related stigma and discrimination recognizes that strengthening of networks of PLWHA, (sometimes called “networks of positives”), can take the lead in addressing stigma (Christopoulos, 2020; B. Turan et al., 2016b; Turan, 2019; Van Der Kooij et al., 2021). The report also calls for more studies to evaluate anti-stigma and anti-discrimination programs (Camlin et al., 2016; Ruria, 2017; Lazarus et al., 2021; Silván-Ferrero et al., 2021). It noted that this approach integrates the individual and the societal arenas where stigma must be addressed, providing self-esteem opportunities through which participants may overcome potential internalization of stigma. Social “normalizing” of the stigmatized individuals, both for their own benefit and among efforts to alter the attitudes of people that designate PLWHA as “other” must be done (Bonnington et al., 2017b; Demirtaş-Madran, 2020; Petros et al., 2006).

Feyissa, (2018a), in the articles mentioned above, notes that discrimination based on stigma deprives individuals of opportunities that are available to others. Stigma thrives on and engenders difference: specifically, it elevates some groups as superior and relegates others to inferior status. Thus, in order to understand the social forces that create and reinforce this difference, it is imperative to situate stigma along the axis of power, domination and control. This power in turn facilitates “the construction of stereotypes, the separation of labeled persons into distinct categories, and the full execution of disapproval, rejection, exclusion and discrimination (Demirtaş-Madran, 2020; Feyissa, 2018a; Mumin et al., 2018; Rahman et al., 2020). Understanding stigma in terms of power relationships may aid in understanding the particular situation of youth who are HIV positive.

Granted that the identification of the “other” is rooted in social relations of power, and given that the “other” is often the powerless, stigmatization is seen in this way. It allows the designation of different groups of people (such as commercial sex workers, men who have sex with men and people from certain geographic regions) as being not only disproportionately at higher risk of HIV infection (Clores, 2019). However, at higher levels of infectivity there is a threat for the “in groups”. The implications can be many, from denial by the “in group” members of existing behavioral risk in their own lives, to blame and discrimination in its many forms toward the “others”. Like some of the other authors, Bhavsar et al. (2019); Liu et al. (2018); SoHyun et al. (2019) have mentioned that stigma must be understood in terms of institutional or structural

stigma. In this sense, stigma is defined as the stigmatizing of a group of people through the implementation of public and institutional policies and procedures (Farotimi et al., 2015; Jones, 2019; Manjate et al., 2020).

In this literature review, the articles that explored how youths experienced and were impacted by stigma did not identify young people or adults in the populations studied; the study of enacted stigma among youths living with HIV and AIDS did not offer information about differences by age (Green et al., 2016; Hedge et al., 2021; Kiwanuka et al., 2021). Although, some articles cited deficits in health access for youths, on the presence and detrimental impact of stigma for young people. No articles were yet identified that looked at the intersection of concerns highlighted in the present research on their relationship with stigma in the lives of youths (Ankrah et al., 2016; Kimera, Vindevogel, De Maeyer, et al., 2019b; King et al., 2021; Rimawati et al., 2021; P. Shah et al., 2018, 2019; Williams et al., 2017; Woodgate et al., 2017).

At policy level, the epidemic is a serious threat to the country's social and economic development and has serious and direct implications on social services and welfare. Given the high HIV prevalence in the society, and in the absence of a cure, the devastating impact of the epidemic is incomprehensible (Abdulai et al., 2021; Arinaitwe et al., 2021; Bristowe, 2019; Ghiasvand, 2019; Saloner, 2019; Senn et al., 2021). Since its adoption by the Government, Primary Health Care has been the cornerstone of Uganda National Health Policy in its endeavor to ensure success in the delivery of essential health care in the country. the Government through Primary Health Care emphasizes on: Community involvement and ownership through active participation in identification of problem areas, planning, implementation, monitoring and evaluation of health care services; Multispectral collaboration by establishment of Committees involving other Sectors such as Water, Agriculture, Education and Ministries such as Community Development, Gender and Children (Church et al., 2015). The current study identified some suggestions in policy making that affect direct implications on social service and welfare.

## **2.6 Overcoming stigma: individual and social interventions**

Some literature has sought to identify and describe approaches that may help to overcome stigma. One of the interventions identified as constructive in the fight against HIV and AIDS and the role of stigma is “giving HIV and AIDS a human face” (Kota et al., 2021). It is one of many efforts

that include PLWHA in prevention and intervention efforts (Ekstrand et al., 2020; Giusti, 2020; Feyissa, 2018; Nyblade, 2021). However, through this process, PLWHA who are active in public HIV and AIDS programs may have to cope with additional problems associated with being “seen”; just as they are working to overcome public stigma, they may be exposed to more stigma because of their visibility.

A UNAIDS summary of literature on HIV-related stigma and discrimination recognizes that strengthening of networks of PLWHA, (sometimes called “networks of positives”), can take the lead in addressing stigma (UNAIDS, 2017). The report also calls for more studies to evaluate anti-stigma and anti-discrimination programs (Srithanaviboonchai et al., 2017; UNAIDS & UNIFEM, n.d.). Moreover, experiences of PLWHA who are members of an existing network will help in forming future HIV/AIDS policies that can be used throughout society and by health care institutions (Alzúa & Katzkowicz, 2021; Feyissa, 2018a; Nasuuna et al., 2021). It is noted that this approach integrates the individual and the societal arenas where stigma must be addressed, providing self-esteem opportunities through which participants may overcome potential internalization of stigma, and social “normalizing” of the stigmatized individuals, both for their own benefit and among efforts to alter the attitudes of people that designate PLWHA as “other” (Mahamboro et al., 2020).

Stigma research has also given considerable attention to a variety of ways in which stigmatized people may use disengagement from the stress resulting from stigma as a coping method (Prinsloo et al., 2017) as cited in (Williams, 2020; Thapa, 2018; SoHyun et al., 2019). The two main forms of coping through disengagement that have been studied are physical and social avoidance of situations in which stigma may be a problem, and denial or minimization of prejudice and discrimination (Srithanaviboonchai, 2017; Nyblade et al., 2020; Woodgate et al., 2017). Research on general stress reactions suggest that certain types of responses to stigma related stressors may be maladaptive, in particular those that sometimes lead to depression and psychological distress (Azia et al., 2016); maladaptive coping responses would also include disengagement in treatment.

To understand how stigma works, one needs to be cognizant of what is at stake for both the stigmatized and the stigmatizer, namely the loss or gain of social status, life chances and good fortune. Yang and associates use the term “moral experience” (Adam et al., 2021; Vellozo et al., 2020), to collectively define what is at stake in a given social world. Stigmatizing conditions



threaten those issues that matter most to the sufferers and non-sufferers. Their health, social status and well - being, or “moral experience”, prompting the non-sufferers to respond to the stigma by protecting themselves from the perceived threat posed by the individuals with the stigmatized condition (Kooij et al., 2021a; Mumin et al., 2018; Paintsil et al., 2020; Van Der Kooij et al., 2021; Varas-Díaz et al., 2019).

## **2.7 Conclusion and Responding to the Knowledge Gap**

In this literature review, the articles that explored how youth experienced and were impacted by stigma did not identify youth in the populations studied; the study of stigma among the youth in the age group of 18 to 24 years did not offer information about differences by age. Although some articles cited deficits in health access for the youth, the presence and detrimental impact of stigma for the youth, no articles were identified that looked at the intersection of concerns highlighted in the present research: what is the relationship between stigma in the lives of youth living with HIV positive, specifically, and their treatment-seeking and other behavior? By undertaking such a study that focuses on youth living with HIV and explores just what the HIV positive youth themselves say, a door is opened to fill an information gap in the literature; in turn, such information will be used to inform the design of any interventions to overcome stigma and to improve treatment seeking and adherence to treatment regimens, specifically among the youth living with HIV.

Therefore, the literature reviewed is relevant and quite informative with respect to the current study objectives. However, most of the studies do not necessarily focus on HIV stigma treatment. Furthermore, the review exposed the dearth of studies that explore the HIV stigma treatment behavior engendered by the context influenced by the prevailing HIV stigma. More importantly, a few of the studies reviewed attempted to explore the connection between HIV stigma and the treatment seeking behavior. The research gaps so highlighted render the current study original and ground breaking.

## **CHAPTER THREE: RESEARCH METHODOLOGY**

### **3.0 Introduction**

This Chapter presents the methods that were used to carry out the study. It presents the research approach, research design, and study population, sample selection, sampling methods, data collection methods and instruments. In addition, it presents, describes and justifies procedures for data collection, data management and analysis, ethical considerations and limitations of the study.

This study adopted a qualitative research methodology. Qualitative methodology refers to research that produces descriptive data including peoples' own words, and records of peoples' behavior. It is a way of approaching the empirical world by understanding people from their own frames of reference; in this case, how youth living with HIV experience reality. In doing qualitative research, the researcher sets aside his or her own perspective and taken-for-granted views of the world. Therefore, qualitative research methodology was adopted because it accorded me the opportunity to attain an in-depth understanding of the perceptions and experiences of stigma in its natural settings, from the point of view of the youth living with HIV and the meanings they attach to this disease.

#### **Philosophical underpinning of the research methodology**

The study is guided by Edmund Husserl's, 1885-1937, phenomenological philosophy. This philosophy's ontological position holds that reality is subjective. It mainly questions what is taken for granted; for instance, the stigmatization of HIV patients by many people who perceive that they are likely to die due to infection; hence, ending up denying them medical services. From this ontological position, the study's epistemological view is that arriving at truth depends more on subjective perceptions. Thus, qualitative methods of data collection (interviews, focused group discussion methods) were considered essential, since stigmatization varies based on each individual's subjective beliefs.

Literature argues that any research undertaking should present the philosophical assumptions that guided the choice of the research methods. Davies (2020) stated that when a researcher picks a method, it is based on a philosophical framework that justifies why that particular method is chosen and it should be compatible with the view of reality held by the researcher. Although there are several schools of thought in social sciences, the dominant philosophical epistemological positions

are objectivism and subjectivism, and they address the question of what should be accepted as legitimate knowledge in a discipline (Bryman, 2016).

Objectivism is the epistemological position that posits that a researcher should detach him/herself from reality and explain it using universal laws (Blaikie, 2018). This implies that reality is pre-given, has intrinsic meaning and the role of the researcher is to discover that meaning (Blaikie, 2018). The intuition of the proponents of this position is that if we are able to observe a plant grow and report on it, then we can also observe human beings interact with their environment and report on them (Blaikie, 2018; Davies, 2020). On the other hand, the subjectivistic epistemological position argues that people construct their own understanding of social reality based on their interactions with their environment (Blaikie, 2018).

Given the above epistemological positions, four research paradigms have been widely adopted in social science research (positivism, post - positivism, critical theory, and constructivism). These paradigms provide the basic set of beliefs that guide the conduct of social research (Blaikie, 2018; Davies, 2020; Piri et al., 2019). One of the authors argues that paradigms provide different ways of making connections between researchers' conceptions of the social world, peoples' experiences and the social world within which social life occurs (Blaikie, 2018). Among the four paradigms, this study adopted the constructivism paradigm that conforms to a relativist ontological position and a subjectivist epistemological position (Blaikie, 2018; Piri et al., 2019).

Constructivism philosophical paradigm is an approach that asserts that people construct their own understanding and knowledge of the world through experiencing things and reflecting on those experiences. It is based on the analogy that social reality is a product of processes through which human beings make sense of their everyday actions and situations. People form or construct much of what they learn through experience (Blaikie, 2018; Davies, 2020; Piri et al., 2019). Blaikie, (2018) noted that constructivists maintain that to understand human action, researchers must understand the meaning inherent in those actions.

### **3.2 Research design**

The study majorly followed a qualitative research approach that seeks to understand and describe the universal essence of a phenomenon. The approach investigates the everyday experiences of human beings while suspending the researchers' preconceived assumptions about the phenomenon. This design deals with a phenomenon under analysis in a situation. Hence, the phenomenon of HIV stigmatization and HIV and AIDS treatment - seeking behaviors among youths were analyzed. This design was considered crucial in the deep analysis of why there is stigmatization among youths seeking treatment, which appears to be a new phenomenon to stigmatize youths seeking treatment. In healthcare, it was used to explore youth's experiences of illness and medical care. For example, it has investigated the experience of being on treatment and seeking health care services in their day today lives. Here, phenomenology focuses on describing what all participants have in common as they experience a phenomenon

Research can be conducted either by employing qualitative or quantitative approaches depending on the desired end results that are envisaged. Due to the sensitive nature of the topic about stigma and HIV, it was decided a qualitative approach to be appropriate. Qualitative research seeks to answer certain questions, to explore issues and to understand phenomena from the perspective of the research participant. It answers all the questions beginning with: why, how and in what way? Qualitative research tries to answer given questions by focusing on the local population it affects, gathering perspectives and insights by conducting interviews and surveys. It analyzes unstructured information. Unlike quantitative research, qualitative research does not rely on statistics or numbers.

Qualitative research is used to gain insight into peoples' attitudes, behaviors, value systems, concerns, motivations, aspirations, culture or lifestyles. It emphasizes the importance of looking at variables in the natural settings in which they are found. Detailed data is gathered through open-ended questions that provide direct quotations. Qualitative research seeks to do all this by using naturalistic methods, which are interviews, observations and ethnography and focus group discussions. Qualitative research uses the natural settings which mean "the lived experiences of real people in real settings are the objects of the study. Understanding how individuals make sense of their everyday lives is the main concern of this study. These methods allow the researcher to qualify the participants' understanding during the research process through further probing

questions. Qualitative research is used to learn about the naturally occurring routines, interactions and practices of a particular group of people in their social environment. The study majorly followed the descriptive design.

This design deals with a phenomenon under analysis in a situation. Hence, the phenomenon of HIV stigmatization and HIV and AIDS treatment - seeking behaviors among youths was analyzed. This design is considered to be crucial in the deep analysis of why there is stigma among youths seeking treatment. It was fundamentally interested in how youth living with HIV are challenged and how non- disclosure of HIV status affects them in seeking healthcare and treatment.

The rationale for the selection of this approach was based on a literature search of various studies that utilized similar methods. The strength of the qualitative approach included the ability to gather in-depth information about the study under investigation. A purely qualitative approach would be appropriate to ascertain valid and well-substantiated conclusions about the perceptions of stigma and behaviors of the youth living with HIV in Kampala. Qualitative research seeks to get empirical but non-numerical information about the world. The method pivots on the belief that there is a full and rounded understanding of the youths' experiences of stigma and situations pertaining to HIV and AIDS treatment - seeking behavior.

The phenomenology approach was more suited to research objectives of the study. Piri et al., (2019) citing (Lauterbach, 2018; Van Manen, 2016a, 2016b) noted that phenomenology means describing things as they present themselves to consciousness and two types of description can be identified. One presents the description of the lived experience, while the second describes the meaning of that experience. The second type of description is found to contain a stronger element of interpretation. Therefore, a phenomenological approach that emphasizes interpretative orientation rather than descriptiveness is preferred (Van Manen, 2016).

Qualitative description pivoted on the youth and their environment that provided a more balanced reflection of views of their practices. It illustrates the inconsistencies, ambiguities and the general messiness of youths' life-style as regards stigma, HIV and AIDS treatment - seeking behavior. Besides, it facilitates the interpretation of youths' life - style from the point of view of making a meaning, given by their natural setting.

With interviews, I was able to gain understanding and a rich description of youths living with HIV and AIDS, as well as their personal experiences with stigma. Youths living with HIV and AIDS were in a position to describe their experiences in a detailed form. It focuses on their experiences and reactions to stigma in their lives. Utilizing interviews and seeking the participants' own descriptions of their experiences qualified this study as an ethnographic study. Ethnographic research study aims at exploring cultural phenomena. This research approach involved taking note of the day-to-day life experiences of people as and when they unfolded in the field. Ethnographies are guided by an implicit narrative structure, by a story we tell about the peoples we study (Creswell, 1994). Quite literally, it translates as stories about people: 'a description of folk' (Creswell, 1994), the field study involves a report that reflects the knowledge and the system meanings in the lives of participants. In this case, the participants were the youths living with HIV and AIDS.

### **3.3 Study area**

The research was carried out in Kampala City, the Capital city of Uganda. Kampala city has five divisions namely: Central, Lubaga, Kawempe, Nakawa and Makindye. The study sites consisted of health facilities in Divisions of Nakawa and Makindye. Both the Naguru Teenage Center, China Uganda and Nsambya Mother Care Health Centers were selected because they provide care for everyone and consider health care to be a human right, regardless of an individual's circumstances especially the youth living with HIV. It is in this context that the participants for the interviews were recruited. Health social workers of the respective two centers were contacted to identify the YLWHA where the target age groups were found. Finally, the required number of participants was interviewed from randomly selected youth.

For the qualitative data collection, those health centers serving the YLWHA were considered. Observation of purposely selected health facilities and key informants interviews with direct service providers was conducted. In the next step, local youths were purposively selected for in-depth interviews and focus group discussions.

Available reports show that over 60% of youths with HIV and AIDS are within towns and cities. Thus, Kampala being the capital city might be having a high percentage of these youths with HIV and AIDS, so it was highly important to undertake this study in this context. Kampala city is an

ethnically mixed urban area in Central Uganda. The major ethnic group is the Baganda and the dominant language is Luganda. Typical of many urban communities in central Uganda, the main source of livelihood is industrial production as well as a diversity of business activities.

According to the 2014 census, the population of Kampala was estimated at 1,507,100 people. But about 28,000 youths are living with HIV and AIDS, according to the current HIV prevalence in Uganda (among those aged between 20 to 22 years), making 6.6% (Ssekubugu et al., 2017). Although Kampala has many health facilities, in this study only two health facilities were selected to serve as case studies: Naguru Teenage Clinic under China – Uganda Friendship Hospital and Nsambya Mother Care Clinic under St. Francis Nsambya Hospital. The facilities provide comprehensive, quality health services, specialized care and treatment for people living with HIV and AIDS. This includes adults of a wide diversity. The study was carried out among youths in Kampala Capital City Authority, where the problem of low youths' response to HIV and AIDS treatment was reported to be low. Available reports have indicated that within Kampala Capital City Authority, youths with HIV and AIDS have neglected HIV treatments offered. To address the knowledge gap, our study aimed to characterize the patterns of HIV disclosure and describe its effects on the HIV treatment seeking behavior among youth living with HIV in Kampala City using a qualitative approach.

### **3.4 Study population**

The primary participants of this study were the youth living with HIV. The study population comprised of youths between 18 and 24 years of age, living with HIV and AIDS. The Uganda Youth Policy, however, categorizes a youth to be between the ages of 18 and 30 years. The study participants included both boys and girls. More girls were deliberately recruited into this study than boys, because HIV prevalence is higher among girls than boys (Ortblad et al., 2017). In this study, I focused on the twenty two youth living with HIV as the primary study population, as the core participants. Secondly, the study population included key participants who were health service providers in those clinics, parents, teachers and youth seeking health services, schools, health service providers and families. This was because such participants deal directly or indirectly with people living with HIV and AIDS. The study engaged youth who were on treatment of ART and other HIV health services from clinics for one year to three years.

The study also considered boys because there are great possibilities that the boys could be the ones responsible for enticing girls to engage in sexual relationships; thus they could be a reliable source of some crucial information relating to HIV stigma and health treatment - seeking behaviors. The study further covered health participants because it is those who are handling youth HIV and AIDS patients; hence, they know the extent to which they are stigmatized.

### **3.5 Sampling technique and method**

The study adopted purposive sampling technique and snowball method for selecting the respondents. Purposive sampling is where the researcher sets out to find people who can and are willing to provide the information by virtue of their statuses, knowledge and experience. This technique guided the study in making deliberate choices of people that were privy to information regarding HIV related stigma as an everyday experience among the youth in their respective communities. Since the study was qualitative in nature, it employed purposive sampling and thus the participants were identified purposively and conveniently on the basis of their knowledge and interaction with the HIV epidemic. This sample selection is considered since in qualitative studies, small numbers allow in-depth interaction, thus giving a detailed analysis of the phenomenon under study.

In qualitative research by definition, the researcher does not aim at drawing statistical generalizations and the research approach is field - oriented in nature (Guest et al., 2006). In such circumstances, the use of non-probability sampling techniques has been the practice. In general, the study being qualitative, purposive sampling was applied to select study participants. The first level of selection involved health facilities because this is where the health services were provided as far as HIV is concerned. The second level included youths living with HIV and AIDS within the mentioned age bracket. The researcher targeted male and female youths living with HIV and AIDS for case study participants and in-depth interviews. The study participants were purposively selected due to their possession of basic knowledge and experiences about the phenomenon studied. These enabled the investigation carried out since they were able to express effectively their lived experiences.

Owing to the fact that most HIV - positive people tend to be strongly reluctant to expose their identities, the study participants were also selected using the snowball sampling method (Kirchherr & Charles, 2018). First, the researcher used the networks of HIV and AIDS and the health facilities



(as a gatekeeper). The health facilities had a connection to a community of youth living with HIV and AIDS to introduce one HIV infected person. Next, the researcher asked those identified youth who were HIV infected to introduce other infected youth. In this way, the researcher was able to study participants who belong to an anonymous youth HIV community located in Kampala.

After selecting the first few informants in the clinics, the identified informants then kept on referring me to other friends and acquaintances with whom they interact with and experience and perceive rejections and abandonment. These too also referred me to more friends from whom I selected my final sample. The list of my informants sample grew in a process known as the Snowball sampling method. Snowball sampling method yields a study sample through referrals made among people who share or know of others who possess information or some characteristics that are of interest to the research. Snowball sampling was well suited for the clandestine HIV related stigma where people involved do not easily open up because of the perceived negative attitudes and nature of the disease. So snowballing enabled me to get insiders to help me locate people with the requisite knowledge on issues under study through referrals.

The study being of hermeneutical phenomenology in nature, the researcher engaged in a process of self-reflection with a different purpose. The researcher's bias and assumptions were not 'bracketed' away but instead they were acknowledged and embedded in the interpretive process. Throughout the research process, the researcher acknowledged his own experiences and the way in which the experience relates to the issues researched on.

### **3.6 Trustworthy and credibility**

The truth value asks whether the researcher would establish or find confidence in the truth of the participants in the context in which the study undertaken. In qualitative research, credibility happens when the study presents such accurate descriptions and interpretation of human experience that people who also shared that experience would immediately recognize the descriptions as holding truth (Sandelowski, 1986). The strategies to achieve credibility, the findings, and the interpretations that were based on those strategies and findings, found to be more credible if the researcher could demonstrate a prolonged period of engagement, provided evidence from interviews, and triangulate the data that was collected. The study followed the model of "trustworthiness" as expected of any qualitative researcher (Patton, 2002). The four aspects of trustworthiness that are applicable to qualitative research, mentioned below, were addressed, as it

was suitable for this qualitative study. The criterion “truth value” was addressed through an assessment of the findings. In qualitative research such as in the current study, credibility remained the measure of “truth value”. In qualitative research “applicability” was assessed through internal transferability. In qualitative research it was addressed through dependability. The criterion “neutrality” was addressed in qualitative research it is addressed through conformability (Padgett, 2008).

### **3.7 Positionality**

This section details my experience as the researcher and the problems I faced regarding the use of methods selected and rapport building, personal crisis including the good and bad times as well as how I overcame them during the fieldwork. In doing so, I shared my experiences for the benefit of the coming generation of social workers to learn from and be informed as to what it takes to be one.

As I had lived with some youth and sought to understand how they construct meaning, I am beginning to understand what countertransference (Thirsk & Clark, 2017) a psychological term of emotional-cognitive and behavioral responses to clients in therapy or at least those responses that are potentially problematic, looks like in my life. There have been times when I have been unable to address some concerns because of my own fear of confronting my issues of loss and anxiety. The greatest difficulty for the researcher in seeing the world through the hopelessness of bad objects is that the researcher, seeing the world through empathy with the patient's despair, would come to feel as hopeless as the patient did. As a researcher from a different District, I needed to be aware of my own tendency to colonize the work that I was doing. Colonization meant that HIV and AIDs are on the body but do not make me sick. People who are colonized will have no signs or symptoms. The question remains, how are the youths benefiting from my research? As Di Masso et al. (2019) points out, there is a tendency on the part of researchers to interpret people's behavior so that it makes sense from their point of view.

Since, I have been working with the youth for some time in Rakai where HIV and AIDS were first pronounced. This is the tendency a researcher has to over-identify with the culture or group observed. In so doing the researcher can lose his/her own sense of identity and analytic stance. The researcher reacting emotionally to the interview observations is evidence of this. Like a personal confession, maybe there are times when I have feelings of anger that are buried deep within. The

academics of studying, writing, and reading keep me insulated from my own issues. It is, in effect, to become acquainted with ourselves. To the extent, therefore, that our research helps us to conceptualize the content in our unconscious thought processes, they help us, as we are trying to help them. I look back and see how I have made mistakes and been unforgiving to myself.

When interviewing and considering research with HIV and AIDS patients, it was necessary for the researcher to read extensively about their situation or, if one can, work to develop a relationship with these youth. After taking some time with participants in selected centers, the youth began to trust me and share their stories. As a potential researcher, I had the privilege of having a relationship with them. As Aristotle would say, the youths had embraced the virtues of my heart. They know I care about them and I work hard to respect them as equals. Reflecting on this thesis, I too wear a particular mask; it might not be the mask of survival. The question that keeps reverberating in my mind is-what does my mask look like? How could I maintain the persona of a researcher and not intentionally become a social worker or friend? I realize the lines would be blurred and if I am aware of this; hopefully I took the necessary precautions to keep the interviews as “clean” as possible.

Coping involves navigating a course between these two extremes and ultimately creating a set of assumptions that could account for the stigmatized experience, yet provide some modicum of personal solace. In essence, youths struggle to move toward their old assumptions, while developing a new worldview that allows for the possibility of misfortune. Social support is particularly helpful following stigmatized life events, for caring, others provide strong, direct support that the world is benevolent and the youth is worthy.

The losses and uncertainty youth experience forced me to think about how I interpreted the lives of others. The language and meanings were ever changing. The issues became more and more complex and ambiguous at the same time. Yet, the element that remained the same was the need for a relationship. They are a source of life and a lack of them can lead to death. They are what put smiles on youth faces and hope in their hearts. As I have observed them, just knowing someone cares, listens to their stories, and gives them something no one can take away makes them satisfied and content. My goal was to keep listening, learning, and interpreting. The stories were ever changing. The meanings I was attempting to understand could be life giving and hope-filled. The effects of stigma were ubiquitous among the youths.

### **3.8 Data collection method**

The study employed primary data from the field and secondary data from existing literature. To understand how stigma affects the treatment-seeking behavior of youth living with HIV, its drivers, risks involved, and coping strategies of coping mechanisms of HIV stigmatized youth, the study employed, in depth interviews which is a qualitative research technique that is used to conduct detailed interviews with a small number of participants. In contrast to other forms of qualitative research, researchers using an in-depth interviewing approach invest a significant amount of time with each participant employing a conversational format. Key Informant Interviews (KIIs), a qualitative in-depth interview with people who know what is going on in the community. The purpose of key informant interviews was to collect information from a wide range of people—including community members i.e. parents, teachers and health service providers who have first hand knowledge about the community and the youth. Focus group discussions (FGDs) a qualitative approach to gain an in-depth understanding of social issues. The method used to obtain data from a purposely selected group of individuals rather than from a statistically representative sample of a broader population. The life histories were also used as data collection methods. Later, in depth interviews (twenty youth and two life stories) were conducted with the youth (male and female). These were accompanied and informed by extensive key informants that included; parents, teachers and health service providers. Furthermore, ten (10) Focus group discussions were held with groups of male and female youth living with HIV. All these data collection methods were used in order to increase credibility of the qualitative data collected and to facilitate the triangulation of the data as these methods would ensure diversity of informants as explained in detail below.

#### **3.8.1 Interviewing for in depth**

An interview is an oral, in-person administration of the research instrument to each member of the sample (Gay, 1996). If well conducted, an interview can produce in-depth data that may not be possible to get with a questionnaire (Hennink et al., 2017; Lauterbach, 2018). I purposely chose to use in-depth to explore the challenges YLWH face in their daily lives and understand their perceptions of themselves, healthcare professionals and services, and their social spheres via their expressed lived experiences in the healthcare setting. In the study, an interview guide was constructed and administered to the participants. A key informant interview method has been

widely used when researchers seek to obtain expert source information (Pourjam et al., 2020; Thorne, 2017). The study chose key informant interviews because the method proved efficient in collecting data for the phenomena under investigation. This requires engaging with and trying to understand individual and/or group constructions relevant to the enquiry.

The other strength of using an interview guide in both the key informant and in-depth interviews is the depth it allows the researcher to explore with the participants, having prepared in advance a range of applicable items in writing. Furthermore, it helps focus the discussion and provide a structure for the sensitive conversation. Some of the weaknesses of an interview guide could be its length and the depth, sought through sensitive questions. These aspects might deter participants from disclosing their reflections either at the beginning or in the middle of the interview. Another considerable weakness may be the challenge of overcoming cultural and language differences between the interviewer/researcher and the participants.

In addition to that, a research interview is a specific form of human interaction in which knowledge evolves through a dialogue (Kvale, 1996). Interviews in this study were chosen because they create an access to the interviewee's world, and their lived meanings. This enabled the researcher to understand the meanings constructed by the youth living with HIV and AIDS. The interviews also helped to capture experience that happened at some previous point in time, which could not be captured through observations in the Focus Group Discussions. Interviews were conducted with youth living with HIV and AIDS and key participants, from May to December 2021. The researcher conducted these interviews himself to make sure all the relevant topics were covered and that probing themes that seemed relevant in the interviews were done appropriately. There were ten focus group discussions and twenty two interviewees who were contacted, these were youth living with HIV and AIDS, two participants followed up for two months for the in- depth case study. The key participants were contacted through the centers to clarify on issues of relevance to the topics that were identified from the participants' narration in the second interviews.

The interview guide was designed based on the study objectives. Each objective had questions pertaining to it. The researcher asked questions while taking notes and recording key responses from the study participants. The plan was to conduct repeated interviews with the core participants until no new themes emerged from the follow up interviews. This was not the case with some of the participants who were reported to have been relocated by the time the researcher tried to contact

them for follow - up interviews. At the beginning of each interview, participants were asked to give their demographic information. The interview guide was considered essential as it allowed the researcher to ask pre-emptive questions, which would allow the capture of vital information from the study participants.

Key informant interviews (KIIs) are carried out with observant, reflective members of the community of interest who know much about the culture and are both able and willing to share their knowledge. In using key informants, one chooses them strategically, considering the structure of the society and the content of the inquiry (Nyumba, et al, 2018). Relying on the informants on my contact list I had put together at the start of fieldwork, together with more informants I got from these informants' networks, I drew up a list of key informants that were used to inform this study. Using an interview guide, I conducted fifteen KIIs with: five teachers, five parents and five health service providers. All these informants were each selected using the snowball sampling method, and they each were directly or indirectly related to the issue of HIV and their different daily experiences. The interviews with the key informants took place at their work stations where a recorder was used, and I also took down notes during the discussions. As for the teachers, the conversations were held at their schools while others (parents) were held at their homes.

**Table 3- 1: Showing the key informant interviews done by participants and gender**

Informants	Gender	No. of Informants
Teachers	Male	2
	Female	3
Parents	Male	2
	Female	3
Health service Providers	Male	3
	Female	2
Total		15

### **3.8.2 Participant observation**

The study also relied on participant observation as a method of data collection. Participant observation is a research method involving data collection by means of participating in the daily life of the informants in their natural settings (Brenner, 2021). While using this method, a researcher involves themselves with members of the community, talking, observing, listening and trying to understand the world from their point of view in order to be able to intellectualize what he or she learns, and then put in perspective and writes about it convincingly (Brenner, 2021). To understand society, a social worker has to traditionally immerse themselves in it, learning as much as possible, to think, see, feel, and sometimes act as a member of its culture, and at the same time as a trained anthropologist from another culture (Rosenfield, 2016). Using an observation for case study, I was able to take part in the daily routines of the two participants for a full month in their respective places as I observed the community members at different levels treated them. Decision regarding selection of the two participants was based on the research questions, theoretical perspectives, and evidence informing the study. The subjects sampled were able to inform important facets and perspectives related to the phenomenon being studied with their consent.

In addition, ethnography is appropriate for the study of sensitive phenomena, which living with HIV qualifies for because of its nature. Sensitive research refers to the study of secretive, stigmatized, or deviant human activity and behaviour involving vulnerable research subjects (Li, 2008). As a result of its sensitive nature, YLWHA were in the beginning wary of my seeking information about their way of life. But, ethnography provided me an opportunity to stay in the field for one month which facilitated me to build rapport and gain the youths' confidence. With the ethnographic design, I was able to observe, and interact with the youth and general community about life in their daily activities, listened to their fears, uncertainties, survival strategies, opportunities and the meaning of living with HIV in their lives which I could not do with a survey where there is little room for probing. Besides, using ethnography provided me with an opportunity to document my own experiences and interpretation of HIV medication side effects and low HIV risk perceptions as I interacted with the youth, while at their respective communities.

I noted the kinds of behaviors and attitudes people have towards youth living HIV. In doing so, I witnessed the way some relatives behave and treat their brothers and sisters who have the disease in their homes. I also observed and interacted with some of the relatives and parents involved in taking care of the youth, establishing their roles, the patterns of behaviors, how the family members

communicate, risks faced and survival strategies of the youth. I even paid attention to the relationship between the parents and friends, as well as noted the opportunities that draw people to negatively reject these people living with HIV. Participant observation enabled me to observe as well as interact with the youth as they went about their daily activities. When I think back, this fieldwork observation did not only draw me closer to the world of people living with HIV and AIDS, but equally gave me a tremendous opportunity for spontaneous research practice. For instance, while in the field, I usually sometimes interacted with people seeking for more information about epidemics. I also used boda-boda for travel as I moved from one place to another. In doing this, I desired to make myself acceptable to the community in order for me to be allowed to observe the exchange process and all the happenings at the community level. While in the field, I interacted with youth and observed events as they unfolded in their respective families. To avoid bias when interacting with members in families and communities, I needed to be aware of my own assumptions, empathize with different perspectives, and communicate respectfully and effectively.

It was possible to see the family members treat and behave with these youths. It was also possible to see the different ways in action, gestures. Besides, whilst moving along the participants, I engaged in conversations with some people along the way, and was able to observe the gender composition of the youth moving at different hours of the day as well as take note of the interactions between youth living with HIV and those who are not. I noted that young women are the bigger bulk of stigma though the young men-controlled their emotions. While there, I observed how HIV positives are treated in places of health services and care. I also witnessed how health service providers behave towards youth living with HIV. Still in these clinical centers, I met and conversed with the doctors and social workers with whom I discussed about the benefits and contests of being a youth seeking treatment from their centers and how living with HIV experience impacts their lives. The service provider reminisced about the history of people with HIV and AIDS in Makindye, and even went ahead to explain how the disease has ruined youth development to date as well as their hope for the future. The data was collected in 2018 for two months.



### **3.8.3 Life Histories**

Life history (LH) is an attempt to define the growth of a person in a cultural setting and to make theoretical sense of it (Denzin, 2017). It involves in-depth interviews centered on a detailed appreciation of the life of an individual as lived revealing new perceptions on the occurrence under study. Life history grounds stories of personal experiences and perceptions in their wider social and historical context, and pays attention to social relations of power (Duggleby, 2016). Consequently, by encouraging and allowing people to tell their narratives to researchers, participants are given a chance to make meaning of the experiences (Denzin, 2017). Using an interview guide as attached in the appendix; I recorded two life histories of two youths with one being a young woman while the other one was a young man (one of the selected male and female were living with HIV for over three years). These re-counted their life histories to facilitate me in grasping the trails that have brought them where they were at the time of doing the fieldwork. All the participants whose life histories were documented had been carefully selected from my contact list, which I had created, for these youth had exceptional tales about their lives, which drew me to ask them again and again. The two youth narrated how they have been treated by their colleagues' right from their respective homes, schools and outside their communities. They highlighted the way they were denied to share resources in the home and opportunities to further their education. They also described how they receive information from their peers who speak ill of them when they move around the village. They explained the meaning of having HIV at a tender age, the risks they face and their survival strategies, the benefits accrued in the process, as well as their love-hate relationship with community members especially friends, parents and relatives.

### **3.8.4 Focus Group Discussions**

The main purpose of focus group discussion was to draw upon participants' attitudes, feelings, beliefs, experiences and reactions in a way in which would not be feasible using other methods, for example observation, one-to-one interviewing, or questionnaire surveys. A focus group is a group of individuals selected and assembled by researchers to discuss and comment on, from personal experience, the topic that is the subject of the research (Nyumba, 2018). Focus group discussions (FGDs) are a qualitative research method. They consist of moderator guided interactional discussions about a predetermined topic involving six to ten participants from similar backgrounds in order to generate rich details of complex experiences and the reasoning behind an

individual's actions, beliefs, perceptions and attitudes (Nyumba, 2018). The participants in FGDs are deliberately selected as they should present similar socio-characteristics and be comfortable talking to the interviewer and each other in order to focus on a given topic (Thapa, 2018).

I engaged in eight focus group discussions with the youth at the clinical centers. The groups constituted six (6) to eight (8) people per group. The FGDs were only eight because in the first two months I was still building rapport and finding my footing in the field, while the last month I was wrapping up and closing any loose ends. Thus, given the limited period for the fieldwork, I carried out two FGD per every two weeks in order to have time to be able to attend to the other selected methods of data collection. A note taker assisted me during the discussions.

FGD method was selected to assist in pinpointing possible areas of further enquiry and help in explaining about stigma related issues that may have eluded other research instruments. Focus group discussions for youth living with HIV and AIDS have been widely used as a qualitative approach to gain an in-depth understanding of research issues. The major merit of the technique is that it allows the researcher to assemble a group of individuals to discuss a specific topic, aiming to draw from the complex personal experiences, beliefs, perceptions and attitudes of the participants through a moderated interaction (Nyumba et al., 2018). The researcher internalized and examined the different views given by the participants.

Ten Focus Group Discussions were carried out with the following groups of people: female participants living with HIV were met at their respective clinics i.e Naguru Teenage center and Nsambya Mother Care. Two FGDs were held at Naguru teenage center on different days, and included diverse young women who regularly visit the clinic. At the center, one FGD constituted of youth who normally come for medication; while the other three group discussions carried out on different days included female youth and male youth who usually come to get their ARVs and other health services provided by the clinic center. Then, the FGDs at Nsambya Mother Care consisted of a diversity of male and female youth. The health service providers and community members whom I interact with, the youth on various occasions in their daily experiences. Their interactions with the health providers made them well suited as informants for the study.

In one occasion the discussion groups comprised six (6) to eight (8) participants, and were gender based with female and male's discussions held separately. The separation on the basis of gender was done to give room for each category to express themselves as freely as possible without fear

of being chastised. This is against the backdrop that many female youth with HIV expressed their discomfort at airing their experiences, especially their survival strategies in coping with the disease in the presence of men, some of whom could have been their husbands. So, in order to allow for free expression and realize more truthful information, I chose to talk to the female youth separately from the males so that each would talk without fear of embarrassment.

During the discussions, I was the moderator and my research guide was the note taker. I highlighted the topic of discussion, gave the participants a chance to respond while probing further to provoke for deeper discussions along the objectives of the study as much as possible. I aimed to understand the history of HIV and AIDS, how stigma affects their seeking for treatment, the community, and the risks faced in seeking health services, coping techniques innovated, and the benefits of getting treatment in the general community.

At the start of each discussion, my research guide kindly (the health provider) introduced me to the participants at the different centers, providing me with a platform to explain my research intention to my informants as he reverted to note taking. The discussions were conversational in nature, and provided the study with general findings which served as a vital reliability check about other data collected using other data collection methods. Also, the collected information served as a push for me to dig deeper about some new issues that came up during such meetings. The discussions were carried out mainly in two languages: English and Luganda in both of which I am fluent.

### **3.9 Data Analysis and Processing**

#### **Transcriptions**

Kansiime, (2010), as cited in (Kroidl, et al., 2019), says transcription in itself is an interpretative process. Since the informant's experiences of different phenomena were reported according to the phenomenological tradition, the ambition has been not to make interpretations in the collection and transcriptions of interviews. The interviews mentioned above were transcribed verbatim. The quotations were given in their original form in order to be more real and lively. In Uganda, English is used, and sometimes it is blended with local languages. The words and expressions from the transcripts were explained in text as they occur. In the Ugandan English context, it is also common to use expressions that might not make sense for people who have not spent some time in Uganda. In addition, these were reported in their original outcomes and explained in the text.

Above all, the interview material in this study was analyzed from a phenomenological perspective, in the sense that information was understood from the informant's own perspectives and experiences, how they describe the world and how they experience it (Buehring & Bishop, 2020). Below follows a description of how the collected data were handled and how they were analyzed.

The data were analyzed qualitatively in line with the key themes of the study using content and thematic analysis techniques. The first step in the analysis of the data consisted of reviewing and categorizing the textual data under different themes that were of interest in the study. The transcriptions were organized according to the research questions that were set out at the beginning of the field work. The analysis was done by carefully reading through the transcripts, again and again, and dividing it into meaningful analytical units that facilitated easy description of all aspects of the data. Once I located meaningful segments, I coded them by marking the segments of data with descriptive words, or category names.

Then, the field notes were also reviewed, systematically, re-written according to the dates, and months in which the data was obtained. I approached the text in relation to particular content according to the research objectives. Thus, rather than analyzing the data as a whole, the data was analyzed according to themes and sub themes along the objectives of the study to ease further analysis. The themes included the manifestation of stigma, its drivers, the risks involved, and the coping strategies employed by people living with HIV and AIDS, from which sub themes were created. These themes were in line with the various research objectives that also guided the thesis write up.

Finally, direct quotations of individual responses or group discussions that could explain the participants' views and bring out their voices were identified and presented in the participants' own words. This was done to give more insight into the issues under consideration. Data sources and use of different methods in qualitative research were developed for a comprehensive understanding of a phenomenon. This implies that triangulation was performed to compare the FGDs and in-depth interview responses.

### 3.10 Research Ethical Considerations

Generally, there are ethical principles for social research of which a few are prescribed below. Gilbert (2008); Kvale. (1996) mention some of the following ethical principles:

One principle is informed consent, meaning that the participants were informed about the overall purpose and design of the study, possible risks and advantages connected with participation and that participation was voluntary. In the study, informed consent was received from all the participants. The participants were informed about the purpose of the study, the main features and issues concerning confidentiality and that participants choose whether to participate or not.

Given the sensitivity of the subject under study, ethical issues related to the research and participants were considered carefully. No reference was given to specific identities of the participant/participants. Informed consent from participants and agencies was obtained. This informed consent assured the confidentiality of their responses held under lock-and-key and only used for the purposes of this study. Furthermore, informed consent emphasized that this study was voluntary and that all participants had the right to withdraw from the study any time or not to answer a particular question. The study took place in the hospital where counselors were around in case someone either irritated or traumatized would be assisted immediately.

Confidentiality was assured and anonymity insured, because contact with participants was necessary. Triangulation of chart data with interview data was undertaken. Before all interviews happened, the participants had to sign a consent form. No participant was subjected to prejudices, stereotypes or biases, either directly or by casual or indirect suggestion, by the research team. Prior to initiating any contact with any potential recruit, written approvals by Makerere University School of Social Sciences Research Ethics Committee (**MAKSS REC 01.18.117**) and The Uganda National Council of Science and Technology (**UNCST SS4571**) were received.

The written application detailing the research study's goals and the protections provided to participants was submitted for approval to researcher's academic institution authority and to that of the clinics where participants were recruited. These requirements existed in order to protect research participants from unethical, risky, or harmful effects. No interviews were conducted until all involved academic authorities approved the proposal. The researcher made efforts to report the findings in a manner that anticipated and avoided the possible misuse or harmful consequences

arising from the study. The researcher ensured that there was honesty and transparency at every phase/stage of the research and avoided fabrication, conflict of interest, falsification and other unethical practice.

## **CHAPTER FOUR: YOUTHS' PERCEPTION AND EXPERIENCE OF HIV AND AIDS STIGMA**

### **4.0 Introduction**

The thrust of the study was to investigate what the study participants understood by stigma and what kind of attitude the youth who have stigma exhibit. In order to adhere to this, the study sought to answer research questions that were formulated to guide the investigation from the perspective of cognitive behavioral theory. The findings provide what was revealed about the perceptions and experiences of the youth living with HIV and their experience of stigma from their families, community members and health providers.

### **Participants' Profile**

It was evident that twenty two participants were aged between 18 -24 years, these were the youths and single. Ten key informant participants were aged between 25-40 years (health service providers, ten key informant participants were teachers), ten participants were age between 41-50 between (parents), while ten key participants were parents of 51 years and above. Demographic profile of the respondents was also described in terms of gender. The study further indicates that the majority of the participants were females, while the other participants were males. Regarding the marital status of the participants as revealed in the study, the data shows that all the twenty – two youth participants in the study were single, while the key informant participants were married.

### **4.1 Target Group**

Targeting groups of youths who were HIV and AIDS positive, between the ages 18 and 24 the researcher handled the perception and experience of HIV and AIDS stigma in the following ways:

The in-depth case study of the youth, the male and female youth were made at the Health care units. There were regular interactions with them for a period of one month. One of the male and female participants described themselves as “Victims of circumstances” The male participant said that his mother is a widow, who is living with HIV, and on ARV treatment; her husband died in 1994 of the same HIV and AIDS but the widow befriended a school dropout. They gave birth to

this participant, who is now twenty-one years of age. The school dropout, who is the father of the informant died in 2012 that was when the mother and her son decided to go for HIV and AIDS testing. They tried it three times in different places and the results were positive. Thereafter, the mother explained to her son what exactly happened.

The male informant describes HIV and AIDS as a “curse” and HIV and AIDS as a “curse”

The young female participant, aged twenty, described herself as “a victim who is innocent”. The parents, both father and mother passed away when she was five years of age. They were living with HIV and they never told her so. The immediate relatives never revealed that the parents were living with HIV and AIDS. Her aunt advised her to go for HIV testing after falling sick from time to time. This happened after completing A level examinations and waiting for results. The HIV results came out as positive. That is when the aunt revealed what had happened before and other relatives confirmed so.

The participant added that:

*“I am not married, have not had any sexual relationship and my relatives never told me what exactly happened to my parents until I was found to be having HIV or AIDS. Testing was done three times in different places and all results proved so”.* (Female participant, 20 -years-oldM010).

One of the participants perceives HIV and AIDS is a “way to death” and fear of disclosing. For her there is no hope of getting a boyfriend, no hope of getting married, so no hope of getting a child. “Death may come but the worry is going without an heir,” commented the participant.

The youth participants in the in depth interviews where twenty- two of them were interviewed individually at different times and in safe places without other people’s interferences. They all had the opportunity of expressing themselves freely. The general perception of HIV and AIDS, according to this group, is that they start by describing it as ‘Walumbe’, slim, Kawuka, Kavera. These words are literally translated as death, slim, virus, and condom respectively. The responses show that HIV and AIDS are commonly associated with death because it has no cure.

**Table 4- 1: The frequently counts from the twenty - two participants indicate:**

Issues	Death	Slim	Kawuka	Kaveera	Total
Number	9	7	2	4	22

The word like ‘slim’ is commonly used due to the way a patient emaciates and becomes a very thin person. The issue of there being no cure and so leading to death any time leads to a stigmatizing situation. Furthermore, HIV and AIDS is associated with fornication, adultery or extra marital sexual relationships prostitution as the major causes. The fear to be associated with such acts leads to fear of public opinion. “The public opinion is always negative,” according to some participants, It becomes shocking to get news that so and so is HIV and AIDs positive.

The participants continued to indicate that stigma is there on grounds of fearing that:

Public sees the youth living with HIV and AIDS as being promiscuous, being a mobile grave – a nickname given to a person who may die any time, fear of not being employed especially in some outside countries.

For some participants showed they are stigmatized and the reasons that were given included:

With public opinion some say that they have ‘bad behaviors’. To some bad behaviors being associated with fornication, adultery and prostitution

*Fear of being isolated, when the playmates ignore you, refusal to share utensils with you(Male participant, 22-years-oldM08).*

On the side of female participant, there is fear of not getting boyfriends and consequently not getting married. The married ones fear that their husbands could easily divorce them, if they happen to know that they are HIV and AIDS positive

*At meeting or any gathering, there comes fears of other people’s looks and whenever there are whispers and smiles, the one living with HIV and AIDS could imagine that they are talking about him or her(female participant, 19-years-oldM06).*



Revelations from the five Focus Discussion Groups (FDGs) were compiled and considered. There were eight youths in each group, males and females. These were youths on treatment and receiving counseling services in Health centers. They were going for the said services on specific days as given to the medical people or service providers. The researcher interviewed them in groups for a period of not less than two hours.

**Table 4-2: Perceptions of youth living with HIV and AIDs were tabulated as shown below:**

Group	Issues raised
One	<ul style="list-style-type: none"> <li>• We fear the negative attitude people have towards us</li> <li>• Expect death any time</li> <li>• We are considered to be prostitutes</li> <li>• Challenged by our family members to give birth to children in order to leave successors</li> </ul>
Two	<ul style="list-style-type: none"> <li>• We are referred to as walking dead bodies</li> <li>• Parents/ guardians living with youth were reluctant to offer them education</li> <li>• Worried to die without leaving heirs behind</li> <li>• There is self-isolation: we avoid most public gathering</li> </ul>

*Source: Research data (FDGs)*

**Table 4- 3:Experiences of youth living with HIV and AIDs were tabulated as shown below:**

Three	<ul style="list-style-type: none"> <li>• Denial of sexual relationship leading to sexual perversions like masturbation</li> <li>• Forced to go for prostitutes in town</li> <li>• Do not fear to have sexual relationship with anybody including relatives</li> <li>• Life had become meaningless</li> </ul>
Four	<ul style="list-style-type: none"> <li>• People do not eat food that we have prepared</li> <li>• Some employers see us as disabled persons</li> <li>• Only waiting for death</li> <li>• Our marriages may break any time</li> <li>• Each one of us is known as ‘akawuka kamumala’ (The virus finished him/her)</li> </ul>
Five	<ul style="list-style-type: none"> <li>• We have family pressure to have children</li> <li>• There is no hope for the future, public has put us on the death waiting list</li> <li>• We are ever receiving threatening comments in schools and institutions</li> <li>• The word ‘ yatomera’ – got an accident is commonly used on us the victims</li> <li>• It is hard to see meaning in life</li> </ul>

*Source: Research data (FDGs)*

The participants in the FDGs were interviewed in rooms or places that were not the Health Units. It was done after their consent and well-planned arrangements. The total participants in five FDGs were forty.

The other set of participants was that of parents/guardians, teachers and health workers. These are called key informants in this report. They were called so because of the experience they have in dealing with HIV and AIDS patients. These key informants were not HIV and AIDS positives themselves but have knowledge of the experiences the youth living with HIV go through. It is understood that any person is either infected or affected with HIV and AIDS scourge. A person is infected because he or she is having the disease and a person is affected because his or her relatives are living with HIV and AIDS or have passed away due to the same.

For the parents/guardians, they experience the stigma as one parents expressed that:

*“According to me, it is worrying, I have relatives, siblings and their children who are positive and I see what they are going through is not fine. The big concern and worry is with the number of youths who are passing away. The increasing number of orphans, because if a person dies say at the age of twenty-four; then his or her children who are becoming orphans are likely to be below six years of age. It is likely for the grandparents to take care of the grandchildren”. (Male key informant*

**Table 4-4: The frequency counts; show the areas in which the youths are stigmatized:**

Cause	Frequency count
Deaths of youths	7
Number of orphans	7
Treatment costs	8

*Source: KIIs (Interviews)*

The teachers who among the key informants showed that awareness of the HIV and AIDS positive youths are being stigmatized. The common symptoms or behavior shown by the youths to display the experience they are going through include the following: being rude to teachers at times, accosts lecturer in case of institutions of higher education, avoiding free association with their fellow students, dropping out of schools or abandoning studies in institutions and universities

**Table 4-5: Shows the symptoms youth display**

Symptoms	Frequency counts
Being rude, arrogant	6
Dodging classes/ lectures	8
Unwillingness to associate	7
Abandoning studies	6

**Source: research data (In-depth)**

The Health worker who formed the third group of key informants describes the experiences that youth go through as not being the best. Health workers see a situation of youths being stigmatized through the comments they make as they come for treatment, they use statements like;

“God cursed them, why should they die like that? We might not get married, why me in particular? And so on”.

The health workers further added that some of these youths are victims of circumstances because they acquired the virus from their mothers, who were already infected.

The other behaviors displayed by youths and their relatives, according to health workers, have the following:

“They go to health units with different health issues and they are only encouraged to check for HIV and AIDS”.

Parents, especially mothers, do not want to disclose their HIV and AIDs status fearing to stigmatize their children; some youths fear to get results after being tested; other youths fear their family members to know their status.

It was further reported that the youths who were infected through ‘mother to child transmission’ are less stigmatized than those who acquired it during adulthood. The stigma reduces in those youths who were tested and informed by their parents/guardians at early stages. The popularity of non-adherence in this population was 29.4% per day. About 1 in 3 people on ART are non-adherent in this population. The level of non-adherence in this population was worrisome given the fear of development of resistance so interventions should be made to minimize this level(Siril et al., 2017).

The study showed a large number of perceptions about HIV stigma. The participants revealed that getting HIV is a punishment for bad behavior. Some of the participants in this study said persons with HIV have themselves to blame and other participants felt that if you have HIV you must have done something wrong to deserve the illness, while some participants expressed that the names of HIV and AIDS patients should be made public to avoid spreading of AIDS. Again, a large number of participants reported having difficulty relating to people living with HIV. One view is seen below:

*“At one occasion, one who was suspected of being infected with HIV was not welcomed in the group where people were drinking”. “They do not talk to them or do things with the people who are HIV positive and they think less of them”. (Male participant, 21 -years-oldM014).*

Most of the participants felt that they would not date a person with HIV while some felt that people with HIV should be isolated. These results portrayed that participants felt uncomfortable and afraid and did not want close contact with people with HIV and AIDS; the closer the contact and the more likely that transmission could take place, the more they responded negatively.

The study indicated that perceived community stigma was higher in general than personal stigma. For instance, some of the participants felt that if a family member has HIV, people in the community would keep it secret. Most of the participants thought the community blamed people with HIV and that they should be ashamed of themselves. Many participants perceived other community members to think less of someone because they have HIV. It is noted that many participants perceived the community to keep distance from people living with HIV. Some of the participants in this study perceived that people in their community would not date a person with HIV; some perceived that others feel afraid to be around people with HIV, would not hire someone with HIV to work for them and feel uncomfortable around people with HIV. Many youth have suffered rejection from their families, spouses, friends and colleagues. Rejection was related to the perception that HIV and AIDS results from bad behavior and lack parental respect. For example, one participant said:

*“Some people chase away their own family members because they are HIV positive”. “People used to think less about a youth who is HIV positive and they reject them”. (Male participant, 18-years-old M03).*

Some of the youth perceived others not wanting to be friends with someone with HIV. Some youth from different Universities in Kampala felt that others would not like children with AIDS in the same school as their children and think the community would not drink from a tap if a person with HIV had just drunk from it. Youth living with HIV and AIDS are avoided by others, often because of the fear of causal transmission of HIV. Avoidance may take the form of not wanting to share items or to buy food from a person who is HIV positive. For instance, a participant observed:

*“They say do not go and visit their houses and go to their businesses because you are going to get AIDS”. “People were saying that we must be careful, that person is HIV positive, if we buy food”. “They didn’t want to drink water in a tap where a person with HIV has just drunk”.(Female participant, 20-years-old F02).*

Stigma in this age group is internalized by youth living with HIV and AIDS. This can cause serious consequences on their emotional and physical well-being. The youth in the study say adults do not often take them seriously when it comes to mental health and many of us feel uncomfortable to speak out about our worries for fear of the consequences, and that is where stigma starts. Sometimes, it is hard to understand what is going on in our head or to be able to explain how we are feeling. However, for some “coming out” about their HIV status and mental health problems can be really empowering and improving our confidence. In addition, how much we believe in ourselves makes a difference.

The participants revealed that they were seen and treated as worthless beings who did not deserve further investments since they were considered unhealthy and expected to die early. Several youths represented in the study reported how they felt, how they were treated as trash; and one described this as being worse than the way animals are treated. A leading threat through these youths’ experiences with stigma was thus that it devalues their lives and makes them feel sub-human. They also started to believe that they were useless and expected others to treat them as such. In their accounts, many depicted a sense of not owning their lives and carrying a huge burden of life on

their shoulders. This made them think that life was not worth living and some consequently resented medication.

Consequently, many youths felt that they had to live with a secret and were always on guard to maintain secrecy. Physical signs of HIV like body rashes, persistent cough and weight loss bothered them a lot since they are recognized signs of HIV and AIDS in their respective communities. Almost all participants reported disguising their medicine not to trigger suspicion. One report said: “One of the participants , narrated how she used to keep her medicine in sanitary pad packs, hoodwinking others to think that she was keeping used sanitary pads and therefore to avoid touching them. Their hyper vigilance, however, was sometimes a basis for others to be suspicious and to institute investigations, especially in hostels”.

Many youths shared the experiences that others were afraid to live with them, thinking that they would contract the infection. While unfounded, it affected their social interactions. The youth living with HIV spoke about both mental and physical health challenges. Because of HIV stigma, such as being avoided by peers, gossip and discrimination, some youth living with HIV reported feeling inferior to their HIV-negative peers and that nobody would want to associate with them. This led to deep feelings of shame and even thoughts of suicide in certain instances. Adults also actively discriminated by warning peers against socializing with HIV-positive youths. In the words of one:

*Youth living with HIV do not fit in with their peers. Let us say you are walking towards them (peers), and then you see them looking aside, trying to dodge you or ignore you, they move away from you. Then you feel guilty and angry, and start having recurrent thoughts of death: should I kill myself using rat poison, throw myself in the lake, or cut my neck and die? What can I do?”* **male participant – 24-years-old with HIV.**

*Youth with HIV and AIDS are isolated. You find adults saying, “Don’t share your clothes with him because he will infect you with AIDS.” It becomes so difficult for the infected person to go on with these insults...”* **(Male participant – 19-year-old with HIV)**

Participants in the study experienced stigma in several situations in which their rights were violated by others at home, families, schools and broader communities. They were reportedly denied equal opportunities to enroll or stay in schools, interact with other people, and to learn new things. Although many of them found schooling challenging, the choice to dropout was made by their parents/caretakers who felt that they were unfit for school based on the health condition of these youth and the prejudicial social views already described. As a result, some of the youths were locked indoors and turned into slaves. Within these homes, they decried being subjected to disproportionately excessive domestic chores that involved cleaning, laundry, looking after domestic animals and cooking.

One of the youth participant's accounts in the quote below is illustrative of the distress he felt as he struggled with the injustice brought about by HIV-related stigma in his family, as shared by many participants. Participants felt overwhelmed by such demands and voiced concerns of how they would manage given their flimsy health.

*I was made to do all the house chores in the home while my other siblings go to school. They just made me a maid to work for others” (Male participant, 19-years-oldM02).*

In addition to the experience of domestic and occupational injustices HI related stigma is experienced through being denied basic needs such as food and clothes. Some reported being fed on leftovers and sometimes spoiled food and having to eat alone while others were sharing a plate. They also reported staying in horrendous situations within their respective homes. Below is one such case.

“A female participant, an 18-years-old youth, felt the injustice when she was made to eat poor quality leftover food as others at home would feed on better fresh food.”

Internalized stigma came about because of negative treatment and referred to feelings of shame, embarrassment and low self-worth. Youth living with HIV often isolated themselves in order to avoid exclusion by others, as is seen below

*“You start withdrawing from your friends. You stay in the house feeling lonely. You refuse to join peers because you know they will talk about a person who is HIV positive whom you [probably] stay with...” – (Male participant, 20-years-old with HIV M012).*

The youth living with HIV and AIDS in these two Divisions, shared with me some stories out of their many experiences. Some of the service providers in the category of key participants (KIs) also had their own stories to tell. For some, having worked with people living with HIV in the health centers has subjected them to some sort of stigmatization, as they have been rejected in their places of residence. However, it is noteworthy that most of the service providers did not disregard them. However, they too shared with the researcher some of the bizarre and absurd experiences that their clients have shared with them, regarding stigma and rejection. Through their own experiences, the most affected were youth aged 18-24.

#### **4.2 HIV related stigma prevalent among the YLHIV**

In comparison to Divisions of Kampala, these two Divisions were affected by the HIV epidemic due to difficulty in accessing antiretroviral therapy and logistical challenges in accessing clinical care (Bongomin et al., 2019). In the case of HIV-related stigma, although most attention was paid to YLWHA living in Divisions of Kampala, the studies have demonstrated that YLWHA in two Divisions of Nakawa and Makindye experience a high level of HIV-related stigma. For example, one study in Makindye Division showed that internalized stigma has increased over time among YLWHA.

Some participants raised an issue of “fear” of being stigmatized; that is, they felt that they might be discriminated or rejected by members of the family and community as expressed by one of the participants:

*I rarely take my tablets on occasions when my friends and members of the neighborhood are around my house and have never shared any information about my HIV status with them. I did not have the courage to take out my medication. I always find it difficult to hide this medicine because I live some two colleagues and I fear if they see my ARVs they will tell others, I am infected (Male participant, 20-year-old M09)*



In Focus Group Discussions, a question asked whether there are things people say about YLHIV. Participants asked further on what people in the community say about them. When asked about the forms of HIV-related stigma prevalent in their area, participants cited various forms.

Participants expressed fear and negative consequences if their HIV status was disclosed to their relatives and close friends. They had experienced friends and relatives speaking ill of people living with HIV. Indeed, it was expressed that the fear of rejection prevented some patients' use of antiretroviral drugs (ARVs) from seeking support, even when they were seriously sick, and this may affect their adherence to ARVs:

*The community members do not know my HIV status because I never disclosed my status to them and I will never try it since people have negative perceptions and attitude towards people on ARVs. One day, when I came to the medical center, there was a man who was very sick who stayed in suburb of Kampala but he had come alone to the center because he did not want anyone to know where he was going. People are still isolating us. (Male participant, 22 years old M03)*

The findings presented in Table 4.5.

**Table 4-6: Forms of stigma identified among the youth**

<b>Sub themes</b>	<b>Dimensions of themes</b>
<b>Self - stigma</b>	Social stigma (Perceived stigma) Family and relative rejection Friends and community rejection
<b>Internal stigma</b>	Individual-isolation
<b>Health system stigma</b>	Discrimination in receiving health services Insult of health system staff Ignorance in giving services

### 4.3 Grippled with fear after testing positive for HIV

The youths had several experiences of how they are treated and how they felt about being treated. Some of them were hurt; some were not when their mental health was affected. Participants were asked to describe their experiences with HIV illness and how that hindered help-seeking services. The interviews were recorded with interviewee's permission. Mean duration of interviews was approximately 30 minutes (the shortest went for 21.5 minutes while the longest was 43.5 minutes). The results of individual interviews and FGDs responses on perceived stigma were derived from different forms interpreted. The participants as family and relative rejection, friends and community rejection, self-stigma and social stigma identified these.

Participants feared the negative consequences if their HIV status became known to their close relatives. First HIV is associated with sexual immorality. By being positive, they were already categorized as being unfaithful if they happen to be married or to be womanizers or offer sex in exchange for money. One such opinion is seen in the following revelation:

Youth living with HIV and AIDS are avoided by some members of their respective communities, because of the fear of causal transmission of HIV. Avoidance may take the form of not wanting to share items or to buy goods from a person who is HIV positive. For example, "They say do not go and visit their homes and go to their stalls because you are going to get AIDS". "People were saying that we must be careful, that person is HIV positive, if we buy goods".

Participants experienced changes in relationships when spouses, family members, friends, and neighbors discovered that a particular person was on ART. This is well narrated by one of the participants as follows:

*One day when I came back from work, I saw something unusual from my neighbors. I thought about the situation for some time but did not get an answer. Later, one of the neighbors came and told me what happened a few hours ago. She told me that my son came out with my ARV container thinking that it was a children's play device because when the ARVs are in a tin and shaken, they produce a certain sound. That day, I forgot the keys*

*of the drawer where I usually keep my medicines. One of my neighbors told my son to give the medicines to her and she went to the pharmacy to confirm if they were truly ARVs or not. After confirming, she brought them back to my son and from that day our friendship changed, because previously we used to cook and eat together, but nowadays she is no longer interested in sharing anything with me.... She told other neighbors about it and caused me to be very unhappy. (24-year-old female participant, F002)*

### **Rejection by family members**

When participants asked about their willingness to relate with members of the family, their experiences revealed the family's unwillingness to have relations with YLHIV. It was reported that when people around knew about the patients' HIV status, they forced the patients to leave the house. Some youth living with HIV were denied opportunities to invest in their future because of their HIV positive status. Some people do not want to invest in people who are living with HIV because they think they are not going to live long. For example:

*"Mother denied their money for further training in school for the youth who is HIV positive and give to the younger brother who has more life".***F001is aged nineteen years old** who noted that;

*I live with my parents and have a child. At the time, I learnt of her HIV positive status, I was still a student in one of the schools in Kampala. I know how I contracted the disease, but that I never used to have protected sex. Prior to testing, I used to have fever and body weakness. One day I felt so sick, it happened that her friend who was a fellow student advised me to go to the clinic of Mother Care Nsambya. While at the clinic, the Doctor advised me to test for HIV and other diseases. I did not have the resources but my friend promised to support me. I went back for testing and the results came back positive. I was perplexed and devastated but took courage. I made up my mind to inform my parents and first disclosed to my mother who later informed my father.*She continued thus:

*My father is a physician. When he learned about my HIV positive status, he forced me to leave the house and did not let me live with the family again.*

*He explained that I was a threatening human being for the family members, especially for my sisters. This kind of behavior led me into depression and caused me to delay my treatment (19- year old female participant, F001)*

She had a similar concern that was expressed by her as follows

*It really pained me and I cried a lot. I asked myself, where did I get this disease? Then I realized that I got it from my parents.*

The participant particularly in this case, attributed social stigma to family members' perceptions that all HIV positive people were prostitutes or engaged in sex carelessly and that being on medication means one is about to die.

The participant expressed fear of being morally judged for being HIV positive and on ARVs. Her fears were based on the observation that family members tend to associate HIV positive status with engagement in immoral behaviors, as expressed by the participant:

*I was scared because I was worried about the response of my father and other people close to me in the family. I was concerned that they would want to know how I was infected. So I asked myself, how would my siblings regard me? Will they understand me? Nevertheless, I believe I contracted with HIV when I had a blood transfusion. I have never been a prostitute. (Female participant, 19 years old F001)*

It was established that family rejection is characterized by exclusion, rejection, blame or devaluation that result from experience, perception or anticipation of an adverse social judgment from family members or close relatives. From the findings, participants indicated that stigma is manifested as expressions of fear seen by other family members at the HIV health centers. Participants reported negative perceptions and enablers from the family as they mentioned that the families that were supposed to take care of them when they are sick were the ones who were discriminating and rejecting them.

*“It’s not only in the health centers but also at home. My mother said I must tell my sister about my status. After I told her, I noticed that she changed.*

*She became moody towards me and looked at me as if I am a living grave”*  
**(Participant M05, Group 3)**

*“My sister also wanted to leave me”* **(Participant F04, Group 3)**

*“After I disclosed my status at home I was undermined by my parents and siblings and I was not accepted at home at all”* **(Participant 2, Group 6)**

#### **4.4 Another behavior characteristic that contributes to stigmatization**

One of the negative perceptions of the family was that most youth had trouble being accepted by parents when they disclosed their status. Dominant voices from the youth were of the parents not accepting their HIV status, associating their HIV with promiscuous lives and YLWHA mentioned that parents are claiming that they are an embarrassment in the community. Accordingly, the youth faces a major problem regarding disclosure. The existential belief of embarrassment has nurtured and is a barrier to disclosure, is shown by these remarks:

*“Our parents attend church and they do not want us to disclose our status and do not accept us saying that we are an embarrassment. You become stressed and do not know what to do.”* **(Participant 007, Group 4)**

*“Our parents force us to hide our status because of embarrassment. My mother wanted to hide my status from my father.”* **(Participant F005, Group 8)**

Some of the participants further remarked that the rejection suffered at home could launch an individual on a path of instability, insecurity, immense distress and some instances of suicide.

*“Sometimes parents become angry with you because they think you were promiscuous that is why most people think of suicide when they find out their status”* **(Participant F005, Group 1)**

*“I was rejected and sworn at by my niece when she discovered that I was positive. I was hurt but later accepted the rejection.”* **(Participant 001, Group 4)**

*“I feel that I can’t tell my guardians or parents about my status, and that my life will be shortened and that I will not be able to reach my goals because they will reject me.” (Participant M008, Group 8)*

An alternative voice indicated that some parents are accepting and supporting their children when they find out or discover that they are HIV - positive and is expressed in the following statements:

*“There are some other parents whose behavior towards us is sympathetic. For instance, the father of one of our members understood about the HIV related problems and he educated some of us.” (Participant M005, Group 4)*

*“I spoke to one of the members of the community leaders who promised confidentiality and told me about support groups. At least he was supportive.” (Participant 006, Group 1)*

It was mentioned that the existential behavior of “othering” PLWHA within a family has nurtured the negative behavior of rejection. Some participants reported that HIV – positive people are not welcomed in some communities and this is reinforced by various distressing experiences of rejection at home, not being treated well at work as well as in schools, churches and other public places. In one group, a 22 years female participant (F007) appeared to express shame and guilt and felt that they are seen as “others” for being HIV positive. She mentioned that every time when they watch TV and something is mentioned about HIV, the brother would say there is your “thing” and switch off the TV or change to other channels. The following statement echoed the existential behavior of “othering” of HIV person within the family:

*“If there is a TV program concerning HIV they will often call me and ask me if I have seen my thing.” (Participant 002, Group 3)*

*“They talk about it as if it’s something out there and is for a certain group of people not them.” (Participant 004, Group 6)*

One participant indicated that in the health centers there are some health workers and care providers, especially those who are the age of their parents and guardians, who treat them, as if they own the disease. The following message demonstrates the existential behavior and nurturing of “othering” of HIV youth within the health centers:

*At one health center the health worker in charge mentioned that this is our AIDS. You can see that she is fed up when she saw us and wants to behave like our parents since she is old.” (Participant F004, Group 4)*

### **Family and relative rejection**

Parental influence and its crucial role in shaping the youth in this study is widely acknowledged. Understanding the individual differences in the relationships between parents and the youth is key because the quality of these relationships shapes the development of youth. Different research has focused on personal and social variables that are relevant for youth and the way in which parental behavior, upbringing styles, or educational styles are associated with the personality of this age group. The process of shaping personality is the result of a person’s temperament, the upbringing they receive from those around them (especially their parents), and the relationships they establish with these people.

The issue of family and relative rejection was also evident in the in-depth case scenarios considered in the study. A male youth (M001) at Naguru Teenage Home said that his mother is a widow, who is a patient, and on ARV treatment. Her husband died in 1994 of AIDS but she then befriended another man who had dropped out of school. They gave birth to (M001) who is now 21 years of age. The husband of his mother, who is the father of the participant, passed on in 2012. That was when the mother and her son decided to go for HIV testing and counseling. They tried so, three times in different places and the results were positive as many times. Thereafter, the mother explained to her son exactly what had happened. This attracted mixed feelings of rejection from relatives, who dissociated themselves from the actions of the child and his mother.

*My mother and I tested because I was very ill. My mother had to test because of my illness. (21 - year old participant M001)*

*I was in school and wherever I would step, friends would all keep quiet yet before they saw me, they had been laughing and enjoying. I would keep asking myself why they would keep quiet whenever I approached them. I felt bad and thought of first leaving school then I would go back to school in future when I am okay.*

The above findings were amplified by another key participant, who observed that there was a group of innocent patients, patients of circumstances. He explained thus:

*Two of the youths get involved in those unhealthy sexual relationships when they are below the age of 18. Either their close relatives or boda-boda riders or sugar daddies/mummies sexually abuse them. In most cases, the offenders are HIV and AIDS sero-status. The scourge then spreads when they are in schools, particularly secondary schools, institutions and universities where they freely mix without any serious control* **(24 - year old male participant, M010)**

#### **4.4.1 Friends and community rejection**

Study interview participants cited friends and community rejection as one of the most humiliating experiences. One of the participants noted that he had been pushed away by the community since he was five years old. His classmates humiliated and mistreated him and none of them was allowed to get in touch with or even talk with him. This shows the level of community and friend rejection of PLHIV experience in schools.

Another HIV patient narrated her ordeal of community rejection:

*We have family pressure to have children. There is no hope for the future, public has put us on the death waiting list. We are ever receiving threatening comments in schools and institutions. The word 'yatomera' - got an accident - is commonly used on us the sero-status. It is hard to see meaning in life* **(19-year old male participant, M002).**

The rejection and stigma challenges of PLHIVs further reported to be prevalent in schools, especially with regard to sharing of items. One of the participants asserted:

*Now for example a youth may be at school and his or her fellow students may not want to share plates, bedding or even he or she passes by the student, they start back-biting him or her about his or her HIV status and also keeping a distance from him or her. In other words, isolating him or her.* **(21-year old female participant, F0014)**



One of the participants who explained the situation links the above findings to the feelings teachers tend to have about students with HIV; it was reported:

*There is a general feeling that the infected youth will also infect others, thus they tend to have a negative attitude towards that person They think that he or she is going to infect others. They regard such a person as a social misfit and a sinner. They take this person as a burden due to financial constraints to cater for him or her. (19 - year old female participant, F002)*

Participants reported more manifestations of friends and community rejection, where people do not want to share food with YLHIV. It was reported by one of the HIV sero-status that people do not want to share food with YLHIV. She observed:

*People do not want to eat food that we have prepared. Some employers see us as disabled persons, only waiting for death. Our marriages may break anytime, and each one is described [with such remarks like] 'akawukakaamumala', meaning that the HIV virus finished him/her (23-year old male participant, M007).*

Asked about stigmatization, teachers, who were among the key participants, revealed that they were aware of HIV-positive youth being stigmatized. Teachers reported that this was manifested through the common symptoms or behaviors shown by the youth including being rude to teachers, being hostile to lecturers in case of institutions of higher education, avoiding free association with their students, dropping out of schools or abandoning studies in institutions and universities.

### **Self- isolation**

Among youths struggling with the stigma surrounding HIV, the two reported self-isolation from friends, families, and community members. The fear of disclosure was so strong that many participants expressed an unwillingness to develop new friendships, were afraid to engage fully in their communities, or, in extreme cases, rarely left their home. Once a participant experienced rejection that was perceived to be based on their HIV status they were much less likely to disclose their status again (Kranke et al., 2011). One young woman summarized her self-isolation. To go out and meet people is:

*...too much effort, too much risk. Yes, I, I don't know so much about the younger set of people, but in my particular group you are afraid to tell anybody and so yeah you are kind of isolated, kind of set you in a little group by yourself (24-year-old participant, F011).*

Although both young women and young men recognized this tendency to isolate themselves, fear of others learning about their status often overshadowed their need for companionship.

*I do not have any friends. I got a boyfriend I talk to on the phone ... We just talk on the phone. Huuh, I stay in the house, I stay isolated, I am, and I am very active in my church activities. I sing in the choir and I stay at church from 8 in the morning till 7 afternoons on Sundays. So I am very active in that, but other than that, I do not go anywhere, I stay isolated and it is not good (23 years old participant, F00).*

*You do not allow them to get too close to your life, you know, or to your personal life. You do not invite them into your home. You might join them for certain events and you might even tell little crystal lies, but you just stay protected (21-year-old participant, M05).*

The participants reported that they reduced and cut their social relations and kept away from the community because of stigma. They ran away from it and concealed their illness. It was observed that most sero-status of HIV-related stigma tend to withdraw from the public and live solitary lifestyles. This is in a bid to catch up with the reality of being HIV-positive and appreciating the fact that they are PLHIV. One of the participants explained:

*After finding out my HIV and AIDS infection, I cut my-self off from friends to avoid them knowing about my condition and have wrong judgment about me. I like to receive services from AIDS patients' club, but I am afraid of known by students or colleagues, so I do not take part in club programs. (23-year - old male participant, M009).*

When asked whether there was much fear about contracting HIV, one of the youths observed:

*After realizing that I had HIV, I feared! I thought if I go for health services and people see me, they would begin to despise me; they will stop giving me respect. (20-year old female participant, F0013)*

When asked about fear of contracting HIV, another enthusiastic participant said:

*You know it was a big determination to go for HIV test, something I actually did. However, what caused trouble was fear I developed. To be seen by my fellow youth at the health center and you hear them say out there in the community that “a young man like you go to the health center for sceptorin”. So I felt hesitant to go to the health center. They may say, what were you looking for to get “HIV”; such words disgust me and I totally gave up (19 - year - old male participant, M008).*

Moreover, the hope of getting married is very thin. He ended by noting that the experience is that of going through a life that is meaningless, without any hope.

Another related case is that of the 21-year-old female participant in phase two at the Nsambya Health Care Unit who also described herself as an innocent sero-status. Both her parents passed away when she was five years of age. They were patients, but they had never told her so. The immediate relatives never revealed that the parents were infected with HIV and AIDS. Her aunt advised her to go for HIV testing after she had been falling sick from time to time. This happened after she had completed her UCE examinations and was waiting for the release of UCE results. The HIV and AIDS results came out as positive. That is when the aunt revealed what had happened before and other relatives confirmed so. The informant added that:

*I am not married, have not had any sexual relationship and my relatives never told me what exactly happened to my parents until I was found to be a patient of AIDS. Testing done three times in different places and all results proved so. (22-year - old female participant, Group 08)*

Another participant said that:

*HIV and AIDS is a way to death; for her there is no hope of getting a boyfriend, no hope of getting married; so no hope of getting a child. She adds that death may come but the worry is going without an heir. (23-year old female participant, Group 04)*

Another participant who portrayed that same situation further observed this:

*We fear the negative attitude people have towards us. We expect death any time; we are considered prostitutes. We are referred to as walking dead bodies and parents/ guardians are reluctant to offer us education. We are worried of dying without leaving heirs behind. (21-Years –old male participant, Group 05)*

HIV-AIDS is perceived to make people live meaningless lives, as another participant postulates:

*Life becomes meaningless, there is self- isolation, avoiding most public gatherings and above all, challenged by our family members to give birth to children in order to leave successors. (18-year old female participant, F0012)*

#### **4.4.2 Looking at one with AIDS as unworthy**

It came to my understanding, when I was interviewing and interacting with the youth, probably few things give an HIV-AIDS patient greater dread than the belief among people in society that HIV-AIDS is a sure way to death! During the in-depth case study (ICS), the general perception of HIV and AIDS patients was that society views it as Walumbe, siliimu, kawuka and kaveera. These words literally translated as death, slim, virus, and polythene paper, respectively. The responses showed that HIV and AIDS is commonly associated with death because it has no cure.

The word ‘slim’ is commonly used due to the way a patient emaciates and becomes very thin. The issue of there being no cure and so leading to death any time leads to stigma. Furthermore, HIV and AIDS is associated with fornication, adultery or extra marital sexual relationships and prostitution as the major causes. The fear to be associated with such acts leads to fear of public opinion.

When I interacted and interviewed the youth at Naguru Teenage Home, participants indicated that stigma is there on grounds of fear. I realized from the youths' response that the community sees HIV and AIDS sero-status in different lenses. Thus:

The public sees the sero-status as being promiscuous, being a mobile grave – a nickname given to a person who may die any time. Fear of not being employed especially when their jobs in place like Abdhaubi and South Arabia.

In relation to social stigma in working environments, another participant observed that:

*Some employers see us as disabled persons. There is no hope for the future; the public has put us on the death waiting list. We are ever receiving threatening comments in schools and institutions. The word 'yatomera' – (being sexually reckless and therefore got into an accident where HIV was the outcome). (24-year old male participant, Group 07)*

For the parents/guardians, they experience the stigma as one parent expressed that:

*According to me, it is worrying. I have relatives, siblings and their children who are positive and I see what they are going through is not fine. (38 - year old male parent participant, KI 018).*

The big concern is with the number of youths who are passing away. There is an increasing number of orphans because if a person dies at the age of 24, then his or her children who are becoming orphans are likely to be below six years of age. It is likely that grandparents take care of their grandchildren.

### **Self- stigma**

Self - stigma is identified as a common stigma between PLHIV and it became clear during the interviews that this is what an individual brings to himself through his or her own negative perceptions about him-/herself, based on his/her HIV status. The incidences that enabled us to understand self- stigma included the following:

## **Individual - Isolation**

It was established from the study that participants reduced and censored their social relations and withdrew from the community. The two participants in interviews and FGDs reported that PLHIV tends to run away from stigma and conceal their illness. One participant explained:

*After finding out my HIV and AIDS infection, I cut off my friends not to let them know about my condition and have wrong judgment about me. Those who put AIDS in the perspective of death, may be discouraged from taking medicine because they assume that even after taking the medications, they will still die. He is infected; naturally, fear comes because that person will be thinking about death only. (22-year old female participant, Group 08).*

For the ten participants (health workers, teachers and parents) showed social challenges brought by stigma and the reasons given included Public opinion that they have ‘bad behaviors’, meaning fornication, adultery and prostitution. Fear of being isolated, when playmates ignore you, refusal to share utensils with you are some of the ways the stigma presents itself. On the side of female participants, there is the fear of not getting boyfriends and, consequently, not getting married. The married ones fear that their husbands could easily divorce them if they happen to know that they are HIV-positive. During meetings or other gatherings, there are fears of other people’s looks and whenever there are whispers and smiles, the sero-status could imagine that they are talking about him or her.

### **4.5 Discrimination of PLHIV in health systems**

Youth with HIV and AIDS experiences from stigma showed that some health professionals mistreated them by barking at them and abusing them in public. They pushed the patients away and deprived them of accessing treatment services.

*“There are situations when youth come and want these medicines but when they are not available. Am not satisfied because when those youth go to the health facility to collect the medicine, they are made to stay there for a whole day without even giving them something to eat, yet they do take medicine from there.” (21-year old female participant, Group02).*

An interview participant observed that one time he was supposed to be given two different types of drugs but the health worker gave him a type of drug he was not supposed to take. He complained at the window and was told it combined two. 'It's a two in one type,' they said. The participant was so happy thinking that he was going to take medicine once, but in his words, "*Ooh I was just fooling myself, it really disorganized my health a lot when I took it*".

*'You can find many people lining up to get the services but when they are not catered for on time. Others complain that even the drugs are not enough because even right now you can get evidence of what I am talking of. A number of patients are lining up without being catered for and I think the personnel managing are not enough.'* (23- year old male participant, M019).

The health workers, who formed the third group of key participants, describe the experiences sero-status go through as not being the best. Health workers see a situation of youths challenged by stigma through the comments they make as they come for treatment. They use statements as if God cursed them, why should they die like that, we might not get married, why me in particular; and so on. The health workers further added that some of these youths are sero-status of circumstances, because they acquired the virus from their infected mothers.

The other behaviors displayed by youths and their relatives, according to health workers, have the following: they go to health units with different health issues and they are only encouraged to check for HIV infection. Parents, especially mothers, do not want to disclose their HIV sero- status, fearing to stigmatize their children. Some youths fear to get results after being tested; others fear their family members knowing their status.

It was further reported that the youths who were infected through 'mother to child transmission' are less stigmatized than those who acquired it during adulthood. The stigma reduces in those youths who were tested and informed by their parents/guardians at early stages.

#### 4.5.1 Insults and discrimination in receiving services

Almost all the participants encountered challenges while receiving health and medical services. Most of the patients mentioned such problems as discriminatory behaviors offered by physicians, health professionals' unwillingness in giving services to them and lack of cooperation in acceptance of patients with HIV in hospitals.

*'Am not satisfied because when those youth go to the health facility to collect the medicine, they are made to stay there for whole day without even giving them something to eat yet they do take medicine from there'. (Male key informant participant, 27-years-old M011).*

There are situations when youth come and want these medicines but when they are not available.

*One time I was supposed to be given two different types of drugs but the health worker gave me a type of drug I was not supposed to take. I complained at the window and said it was combined. 'It's a two in one type'. I was so happy thinking that I was going to take medicine once. Ooh, I was just fooling myself; it really disorganized my health a lot when I took it.*

*'You can find many people lining up to get the services but when they are not catered for on time. Others complain that even the drugs are not enough because even right now you can get evidence of what I am talking about, a number of patients are lining up without being catered for and I think the personnel managing it is not enough.' (19-old year male participant, M008).*

Some youth noted scenarios where others had sidelined them in their respective families, communities, and circumstances where they were considered weaklings and not fit to participate in community activities like music and drama, sports and games and other activities that require group making. One 21-year-old female narrated a story on how a coach stopped her from playing netball because she was 'sick' (had HIV). This caused her to feel socially isolated from the rest of the players. Four other male and two female participants continued to say; that it affected them when others taunted them that they are sick and they have a virus. Such words often made them withdraw from possibilities of participating in community activities



#### **4.5.2 Prejudice in receiving services**

Most of the participants mentioned the experience of discrimination in receiving temporary and clinical services; for example, one of the participants said that the doctor ordered that I should be given septrin and ARVs, but I was given only septrin, while others got what they were supposed to get based on what the doctor had. One day, I wanted to go to London with my aunt but was denied a visa at the embassy.

Most of the participants experienced receiving the services along with insult, humiliation, devaluation, mistreatment and prejudices.

*“I was referred to a gynecologist for my checkup. He refused to provide any services to me and referred me to other medical personnel.” (20-year old female participant, F009)*

The participants experienced unkindness during treatment, besides taking a long time waiting.

*“The person at the window ‘dispensary’ was instructed to give me treatment, accidentally gave me two different types of drugs including one I was not supposed to take, which disorganized my life.” (21-year old female participant, Group 03)*

*‘I was told to take two types and she gave me one and told me it's two in one so I took twice a day which was an overdose. I was happy but to realize she did not give the other yet on the form she had indicated given this worsened my life.’ (18-year old male participant, Group 01)*

#### **4.6 Discussion of study findings**

This study sought to investigate in what ways the youth in Kampala perceive HIV and AIDS stigma. Accordingly, research question one also portrays how issues regarding stigma were perceived among the youth living with HIV and AIDS and their surrounding communities in Uganda. Some of the participants in this study perceived that people in their community would not date a person with HIV; some perceived that others feel afraid to be around people with HIV, would not hire someone with HIV to work for them and feel uncomfortable around people with HIV. Many youth have suffered rejection from their families, spouses, friends and colleagues. At the same time, this study shows a rich patterning of enacted, anticipated, and internalized stigma

experiences of PLWHA and provides insights into the myriad of sequels lived through by these youths. In their day-to-day lives, participants revealed being devalued, experiencing fear, lacking future perspectives, experiencing injustice and feeling lonely.

My results resonate with other studies on HIV-related stigma (Brown C; et al., 2010) and theorizations of stigma (Goffman, 1963) in placing devaluation and discounting of people living with HIV and AIDS at the center of stigmatization. Consistent with (Abrams & Hogg, 1988; Hogg et al., 2017; O'Donnell et al., 2018), we found that the social devaluation and discounting often endorsed and expected by YLWHA leading to internalized and anticipated stigma respectively. A foundation for the actions, attitudes, and stereotypes characterized the life of these youth with HIV. The findings indicate that the participants experienced different forms of HIV-related stigma, including verbal, social, and perceived stigma (the fear of rejection associated with disclosing HIV status). This suggests that both intrapersonal and interpersonal fears still exist, despite nearly a decade of increasing the provision of ARV.

The study participants experienced loss of dignity and friendship. Similar findings have been reported in other countries (Campbell et al., 2007). The participants experienced various forms of discrimination, including relational discrimination, blame and rejection by their spouses, workplace discrimination, and mistreatment by health care workers. This suggests that, despite improvements in health status because of being on ART, PLHIV denied services or entitlements because of deliberate actions or omissions by spouses, family members, friends, and/or health care workers. These findings are supported by several other studies (Camlin et al., 2020; Havlir et al., 2019).

Primarily, stigma contributes to fear of disclosure, which has both psychological and practical effects. General psychological consequences are emotional distress, sense of isolation, self-hatred and sometimes-depressive symptoms. In addition to that, consequences shown in this study are that many youths engage in unprotected sex. This is likely to lead to the spread of the HIV virus. Since many people are poor in Uganda, there are also economic consequences, mainly for widowed women and orphans.

By implication, Goffman and others have identified HIV and AIDS as resulting from the socially discrediting attributes. Such attributes have connected the “discrediting” nature of the HIV and AIDS infection to its relationship to historical and cultural taboos such as sexuality and illness, and to ostracized groups (Akatukwasa et al., 2021; Camlin et al., 2017; Havlir et al., 2019). Secondly, living with stigma either vicarious stigma, normative stigma or felt-stigma, generates a large psychological burden. According to Andersson (2020); Wouters (2017), previous research on women in Sub-Saharan African countries shows that women often avoid disclosing HIV infection and therefore fail to seek assistance and treatment, for fear of rejection.

The study at hand points out that the fear is even more evident among the youth and men, since they rarely takes part in group activities or talk about sensitive issues the way women do. Some youth and men are not reached by information or counseling. Thus, they lack necessary information needed for positive living and continue to engage in unprotected sex. According to the results of this study, there seem to be two reasons why men and some youth are not easily reached by information and counseling. Firstly, they seem to fear stigma more than women do and secondly, they seem to be anxious to continue with their lifestyle in the sense of having multiple sexual partners. The findings are shared by (Abrams et al., 2021; Arumugam et al., 2020; Bonnington et al., 2017a), who contend that the role of stigma is “giving HIV and AIDS a human face”. Many efforts have been made that include PLWHA in prevention and intervention strategies. However, through this process, PLWHA who are active in public HIV and AIDS programs may have to cope with additional problems associated with being “seen”, just as they are working to overcome public stigma. They are exposed to more stigmas because of their visibility.

According to the findings, the rate at which the youth make use of their services is still wanting as indicated by the participants. The participants reported during the study that the level of utilization of health services is low when considered with the rate of HIV spread. This is attributed to the fact that youth and other people do not want to test for HIV and AIDS, due to the perceived fear of rejection. It is established that most youth do not want to be seen at health centers and hospitals, for fear of community rejection. This has lowered the rate of utilizing services related to HIV and AIDS. This expression was in the interviews as one of the participants explained.

All in all, the above findings concur with (Pantelic 2019; Somefun et al., 2019), who contend that stigma has created a negative perception of people infected with HIV and AIDS, undermining efforts to reduce the prevalence and spread of the disease. They observed that various scholars have defined the term stigma differently. Bernays et al., (2017) and Goffman, (1963) define stigma as an undesirable or discrediting attribute that an individual possesses, thus reducing that individual's status in the eyes of society.

## **CHAPTER FIVE: YOUTH'S HIV TREATMENT SEEKING BEHAVIOR**

### **5.0 Introduction**

HIV is a virus that attacks the body's immune system. If HIV is not treated, it can lead to AIDS (acquired immunodeficiency syndrome). There is currently no effective cure. Once individuals get HIV, they have it for life. So the study aimed at investigating how stigma has affected the treatment-seeking behavior of youth living with HIV in the age bracket of 18 – 24 years old, in Kampala City. In order to answer this objective, the study sought to answer the following research question “What is the nature of HIV treatment-seeking behavior among the youth living with HIV in Kampala? The ideal situation would be for an YLWHIV to seek medical assistance from medical experts. A person goes to a health unit, he or she is tested in the laboratory and results are known, and then the sick person is treated up to the point of recovery. At the time of the study only ten out of twenty – two participants had just begun treatment while others had been in the program of getting medical services for 1 year to 3 years.

It was revealed that treatment seeking was not a common practice upon confirming the positive status of HIV and AIDS. In addition, fear of rejection, lack of disclosure, denial and being seronegative, belief in witchcraft and spiritual beliefs were barriers identified at individual level. However, following a delay in seeking for treatment, a few factors that brought a positive turnaround included at providers' level: support and good patient-staff relationship facilitated linkage, while negative attitudes and abusive language was reported as barriers to successful treatment. Clear referral procedures and well-organized clinic procedures were system-level facilitators, whereas poorly organized clinic procedures and visit schedules, overcrowding, long waiting times and lack of resources were reported barriers.

For the Focus Discussion Group FGDs), the group participants in five groups gave their views in their respective discussions. The participants showed that the treatment seeking behavior for a disease like malaria is different from the treatment seeking behavior for HIV and AIDS. The symptoms are more emphasized than the cause. There were situations when witchcraft was put at the front instead of HIV and AIDs. The scare associated with HIV and AIDS created a situation

of youth being unwilling to go for voluntary testing. The frequency counts showed results given in table 5.1

**Table 5-1: Showing FGDs responses**

<b>FGD</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>TOTAL</b>
Willing	2	3	1	0	1	7
Unwilling	6	5	7	8	7	33
<b>TOTAL</b>	<b>6</b>	<b>8</b>	<b>8</b>	<b>8</b>	<b>8</b>	<b>40</b>

**Source: Research Data**

The unwillingness to go for testing accounts for higher compared to that of willingness. The relatives or family members also try to hide HIV and AIDS patients by creating other diseases. The common reports given are “so and so is suffering from cancer, Hepatitis B, ulcers, etc.”

Many youths shared the experiences that others were afraid to live with them, thinking that they would contract the infection. While unfounded, it affected their social interactions. Participants seemed to internalize this fear and similarly felt that they were a threat to others as portrayed in their stories. They were highly sensitive to others’ actions, always suspecting them of gossiping or scheming evil for them, as one participant narrates:

*I was in the premises of my workplace and wherever I would step, my colleagues would all keep quiet yet before they saw me, they had been laughing and enjoying. I would keep asking myself why they would keep quiet whenever I approached them. I felt bad and thought of first leaving the job then I would go to work in the future when I am okay”(female participant, 24 years old).*

An individual knows about the social or religious status in society or the family background, adjusting the treatment-seeking behavior accordingly. There are people, including youth, who fear to know about their HIV sero - status. There is even the opinion that “Some youths feel that they are safe when they do not go for HIV testing”. In short, they are not prepared for undesirable results; that is, being told that ‘you are positive’.

The two of the youth participants revealed that HIV-related stigma and discrimination create fear for HIV and AIDS testing among youth in their respective locations/communities. Similar to their employees, the three employers who participated in this study confirmed that their employees fear to test for HIV and AIDS due to fear of challenges of stigma by fellow employees:

*“Some youth working with fellow employees fear to test for HIV and AIDS because they do not want fellow co-workers to know their HIV and AIDS status”.*

*“I think some employees fear to test for HIV and AIDS (one employer prescribed) they do not want their fellow staff to know that their status (the second co-worker, mentioned), may be stigmatized by fellow staff”.*

The findings of this study revealed that the youth fear to disclose their HIV test results because they are afraid of being stigmatized and discriminated against in the workplaces and in some of their respective families/communities. Participants experienced a number of various barriers related to living with HIV and AIDS that were clustered into controlling and management of medication. They are provided at clinic centers and the disease itself; fear, self - devaluation and negative thoughts; lack of meaningful and supportive relationships; reactionary attitudes and behavior from others at different levels of micro, mezzo and macro; and monetary challenges.

The youth living with HIV in the study revealed that social disgrace associated with HIV and AIDS is great. It is so great that there are people who fear buying condoms from drug shops, yet they could need them. There are those who do not know how to use them, and what is worse, they dread being taught how to use them. Ten out of twenty youth indicated that they were born with the diseases and their parents took them to the treatment centers when they were not aware. It was until their parents died that they had to know that they had it. It means being sexually reckless and therefore getting into an accident where HIV was the outcome of HIV and AIDS. Similarly, some said it was until they had persistent symptoms of diseases like constant headache that they were forced to test for HIV infection.

*I tested after having severe headaches and visiting several hospitals without getting any help. The headache started after giving birth. I personally asked to take the test because I was fed up. (23-year old female participant, Group 05).*

*I was born with HIV, so I have lived with it for all my life. I suffered from malaria and headache and then went and tested.(24- year old female participant, Group 03).*

Most of the participants did not have a regular medical worker to care for their health or to consult. Among those who did not have a regular medical worker were those who said it was because they used any health worker they found. When asked what they had ever used when sick, responses given were health facilities, pharmacies/drug shops, self - treatment with local herbs and traditional healers. Regarding what they had done the last time they were sick, the two had gone to a health facility for treatment while some went to a pharmacy or drug shop for medication. Only two participants admitted to having sought treatment from a traditional healer.

Almost all the participants had used a health facility that was outside their communities. Those in this category had done so because the particular health facility offered services not offered by those in their area, while some said it was because the facility offered free or cheaper services. Most of the health facilities visited outside the participants' places of living were public while some were private. The two youth participants had visited a medical practitioner once or twice in the past year for their personal needs, while some had done so for more than three years. Nearly all of the participants had experienced a challenge while accessing health facilities. The most outstanding challenges faced were regular stock out of drugs, high cost of services and long distance to health facilities. High cost of services and long distances to health facilities were the other main challenges established. HIV disclosure patterns can vary by gender, male/female and HIV risk group, and an earlier analysis found that female youth are more open than male youth.

Treatment-seeking behaviors among the youth were analyzed and results presented in table 5.2



**Table 5-2: Nature of HIV treatment-seeking behavior among the youth**

<b>Subthemes</b>	<b>Dimensions</b>
<b>Treatment places</b>	Hospital (Nsambya, Naguru) Health centers (Mother Care and Teenage Center)
<b>Services offered</b>	Drugs (ARVS), other diseases like cough, Counseling services Make follow-ups for their patients Give lots of drinks and eats
<b>Level of utilization</b>	Very low level
<b>Type of seeking behavior</b>	Voluntary after persistent symptoms Parental decision

*Source: Modified Primary data, 2022*

### **5.1 Places where the youth go for treatment and care**

The common places where the youth go for treatment in Kampala City are Nsambya Home Care, Naguru Teenage Centre, Nsambya Hospital and Baylor, for children. The different types of care and treatment provided by the centers are ARV tablets, treatment for other diseases like cough and counseling services. At Nsambya, they also make follow-ups for their patients and give lots of drinks and eats. They offer counseling before someone is tested, so that if you get a positive result, you are already aware of what to do to live a positive life. You also get a chance to chat with other fellow youth and share experiences and encouragement. After that chat with fellow youth, you know that you are not the only one with the infection. One participant said:

*I have a lot of assistance from Nsambya home care, apart from the medicine provided to me; they also give me lots of drinks and eats. (20- year old male participant, M003)*

*There is a way they handle the youth living with HIV and AIDS. First, they do give them different counselors to counsel them and by the way, they do counsel you before you are tested. (21- year old female participant, F009)*

Participants in the Focus Group Discussions gave their two views in their groups. The participants showed that the treatment-seeking behavior for a disease like malaria is different from the treatment-seeking behavior for HIV and AIDS. The symptoms were emphasized rather than the cause. There were situations where witchcraft was cited as being at the forefront, instead of HIV and AIDS. The nature of diseases one is suffering from determines where one seeks medical attention.

### **5.1.1 Clinical Centers**

While at clinical centers, I realized that the accessibility to services, information and educational initiatives concerning HIV and AIDS does not guarantee one's access to proper treatment. The health-seeking behavior of an individual determines their approach towards receiving proper treatment of a disease. I also observed that research on cultural aspects supports the importance of knowledge regarding the disease and the health-seeking behavior of patients. Other significant factors related to the HIV-infected persons and their access to treatment reported in the study were lack of information, prejudice and an unsupportive attitude of healthcare providers, unavailability of a patient's medical history/reports from previous consultations, legal status and use of traditional medicine. It is, therefore, important to determine the health-seeking behavior of HIV-infected persons and their satisfaction with the provided health services, so that their needs and preferences are addressed. One of the participants revealed:

*My first visit to seek treatment was done in Nsambya Mother Care center. Six months after suspecting I did not want to attend health centers or any other medical centers, simply because I grew up knowing that when you visit a hospital, you are supposed to be assisted. I had that bias on health centers and thought that doctors in hospitals could keep my secrets. (23-year old male participant, Group 04)*

Social support is a significant resource for YLHIV, especially those suffering from chronic conditions, including HIV. Social support is positively associated with the psychosocial wellbeing of a person; oftentimes provided by well-established hospitals. HIV is a socially challenging

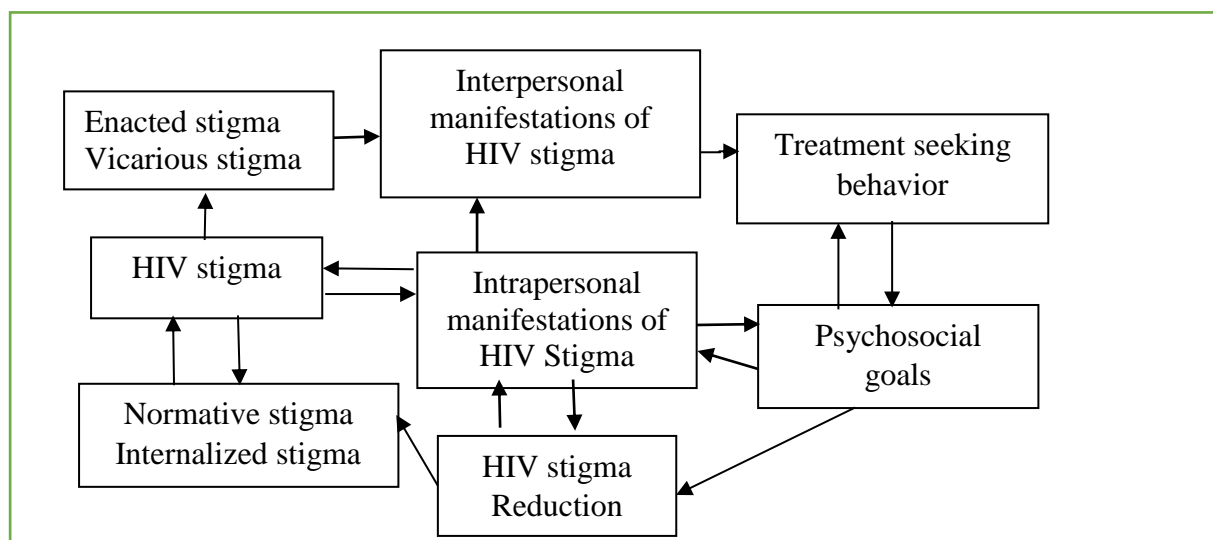
condition because of its association with sexual and stigmatized behaviors. Those infected, particularly older people, often live a socially isolated life, with less social support, resulting in negative health outcomes, including morbidity and mortality. It is therefore evident that youth have unique needs for healthcare that differ from those of adults, so experiences in utilizing HIV care service centers differ.

It was revealing that youth fear to go for HIV testing because they fear challenges of stigma by their friends, in case results come out as positive. They feel a positive result can cause their peers to reject and ostracize them. In schools and institutions of higher learning, students prefer to deal with nurses instead of dealing with teachers and administrators. Some youth fail to adhere to medical instructions. Some teachers behave unprofessionally and rebuke students in public. Students try to avoid such teachers.

### 5.1.2 Feasibility of the stigma treatment-seeking behavior analytical framework

The theoretical foundations of the study in Chapter one and the empirical evidence from the study findings in Chapter Four enabled the researcher to develop and propose a new and more dynamic HIV stigma conceptual framework. The Stigma Treatment –analytical framework proposed. This new hybrid HIV-stigma framework was developed as an attempt to integrate the psychosocially viable aspects of the cognitive behavioral model.

**Figure 5-1:Diagrammatic representation of stigma treatment - seeking behavior (STSB) analytical framework as gleaned by the researcher.**



According to the framework, HIV stigma, being composed of Enacted stigma, vicarious stigma normative stigma, and internalized stigma: directly relates to interpersonal manifestations of HIV stigma. It is also evident that intrapersonal manifestations of HIV stigma act as a result of interpersonal manifestations of HIV stigma. This implies that it relates to social support systems and social networks that can influence individual behaviors, including peers, friends, religious networks, traditions or customs and co-workers. All these call for a viable treatment - seeking behavior to attain the desired psychosocial goals. The psychosocial goals could have an impact on intrapersonal manifestations of HIV stigma and HIV stigma reduction if appropriate mechanisms and viable interventions are developed to realize the expected treatment - seeking behavior.

Therefore, this analytical framework seems to be more dynamic. It involves all aspects of HIV stigma, namely: Stigma-Enacted stigma, vicarious stigma, normative stigma and internalized stigma, interpersonal manifestations of HIV stigma, intrapersonal manifestations of HIV stigma, interpersonal manifestations of HIV stigma, the viable treatment-seeking behavior. The psychosocial goals, all leading to HIV stigma reduction with all the possible appropriate mechanisms and viable interventions geared towards the expected treatment - seeking. The analytical framework relates with CBT in such a way that individuals living with HIV and AIDs are at a high risk of many problems like depression, stigma, quality of life, decreased adherence to treatment, and lack of social support. The present study aimed to investigate the impact of cognitive behavior therapy (CBT) on reducing depression and stigma and improving treatment adherence, quality of life, and social support among patients with HIV and AIDS attending antiretroviral therapy (ART).

### **5.1.3 Health centers**

I realized that for YLHIV the relationship between geographic distance and access to healthcare was unclear. Distant health centers will not attract YLHIV to get services from them. It was found that though YLHIV often faces large economic, social and geographic barriers to accessing healthcare, in some instances, they might go farther than necessary for care. The reasons why YLHIV may travel the additional distance for care point to fear of being identified, labeled and thus stigmatized. Fear of rejection, should they be seen and recognized by members of their community, was one explanation for why YLHIV travel farther to get help. Stigma is a well-recognized barrier to HIV care engagement and retention and ART adherence. Moreover, YLHIV

may travel farther either because they require specialized HIV services, which may only be available at larger, centralized facilities providing tertiary or higher level care, which are often located in urban centers, or because they perceive those facilities to provide more comprehensive or higher-quality care. A female participant explained that:

*There are PLHIV who have not appreciated their status and travel long distances to get medical attention from clinics that are unknown to them. While this may provide them with short-term benefits like keeping their image clean from friends, it has long-term implications, including getting people that are not specialized in HIV AND AIDS treatment. (23-year old female participant, F018)*

This takes a negative toll on youth living with HIV and AIDS and it seems harder for one to reveal one's HIV status, and at the same time seek health services. HIV-related stigma prevents youth from seeking testing, accessing medical care, taking medication and participating in treatment and prevention programs, thus having a profound impact on their physical health.

## **5.2 Services offered at Clinical Centers**

In-depth interviews, FDGs and case study scenarios established that there are different services offered.

Participant number F0023 is aged 21 and married. She resides in the suburbs of Kamwokya. She understood she was positive two years ago. Since then, she has been on ARVs. She narrates that she goes to health centers twice a month and receives these services. However, she is not able to receive all medicine as per prescription.

*“I am satisfied with services provided from this health center and happy with health service providers”.*

This participant, like several others, was satisfied with the quality of care received at the health center; some may not have received services, as they ought to.

### 5.2.1 Provision of ARVS

During the course of interviewing, I realized that YLHIV require care and support, especially on non-antiretroviral therapy clinical services, the treatment of HIV-related infections and non-clinical services that in combination with antiretroviral therapy, contribute towards the reduction of rates of ill health and AIDS-related deaths among youth living with HIV. I personally found out that care and support are important for the following reasons. To facilitate immediate access to treatment when a person is diagnosed with HIV

During the interviews with one of the key participants, he said:

*Access to HIV testing programs expanded so that people who needed treatment referred immediately and supported adherence to treatment.*

He further explained:

*Antiretroviral therapy provided immediately to people who test HIV-positive, alongside comprehensive care and support, counseling and testing, legal, social and economic support, mental health and emotional support and access to contraceptive and health services. (37- years old female teacher Key Informant, KI 08).*

### 5.2.2 Counseling services

I observed during the study that counseling is an important part of HIV care. Counseling is offered around testing and diagnosing individuals and is offered at various stages of development of the infection. It was reported that specifically, counseling on medication use; addressing adherence be initiated before and after starting ART. This may include how to access ART, an issue particularly important for resource-restricted settings. Participants reported that counseling be delivered by health providers or peers. Such counseling is found to successfully enhance adherence by helping PLHIV to cope with the complexity of ART and stigma associated with taking ART. During the study, it was reported by of one of the participants who agreed on the importance of counseling that:

*Counseling is an important component in the life of PLHIV. I recall vividly how my friend took a long time to accept counseling and this cost him a lot. With my case, I accepted counseling first before anything, including testing, and this helped me to move along very well. (22-year old female participant, Group 4)*

### 5.2.3 Follow-up of patients

It was established during the study that follow-up on PLHIV involves contacting a patient or caregiver at a later, specified date to check on the patient's progress since his or her last appointment. It was observed that appropriate follow-up helps one to identify misunderstandings and answer questions, or make further assessments and adjust treatment. During the FGDs, it was revealed that follow-up helps to promote a good working relationship between caretakers and patients. One of the participants aptly opined:

*It would be meaningless, if there were no follow-up on PLHIV. The follow-ups help to identify how they are catching up with treatment and whether they observe their schedules of treatment. Quite often, there are cases where patients abandon treatment and resort to other lifestyles, including drinking alcohol. By following up, we observe all these behaviors and advise our patients accordingly. (29-year old male Key Informant, KI 02)*

During the phenomenological aspect, the in-depth case study, two participants with the first one in Naguru Teenage Home, indicated that he was not ready for voluntary testing. He was not ready for voluntary HIV counseling and testing, until it came to a point when he was falling sick from time to time. Parents identified this as one of the key stakeholders in the implementation of the proposal to prevent HIV and AIDS among the youth. Numerous participants cited the need to involve parents as part of the comprehensive strategy for improving youth health and development and prevention of HIV and AIDS. It was established that this advocacy relies on the assumption that parents are knowledgeable enough to teach their children about sexual topics, including HIV and AIDS.

However, during the study, there was little or no evidence to prove that parents are knowledgeable enough and fully equipped to teach their children about HIV and AIDS. This lack of evidence shows that parents are an understudied and underutilized resource in HIV and AIDS interventions, particularly in Uganda. It was reported that some youth are not willing to test for their HIV sero-status but are forced by their parents (Ssekubugu et al., 2017). It was further reported that PLHIV are provided with supplies in the form of food and drinks. This is important for PLHIV as it helps to boost their immunity. It was found from the study that such supplies are provided by hospitals and other well-wishers that seek to improve the plight of PLHIV.

### 5.3 Level of utilization of health services by the youth

Research findings reveal that the rate at which the youth make use of their services is still wanting. Participants reported that the level of utilization of health services is low when considered with the rate of HIV spread. This was attributed to the fact that youth and other people do not want to test for HIV, due to the perceived fear of rejection challenges. It was established that most youth do not want to get at health centers and hospitals for fear of community rejection. This has lowered the rate of utilizing services related to HIV and AIDS. One of the participants explained:

*If I am to give the rate of utilization of the services in percentage, it is very low. We don't take it seriously and I think it's our culture here as Africans that it's after getting sick that one goes for medical checkups, but when you are still moving on well you can hardly visit such a place. Thus, it is indeed very low. Due to stigma, the sick do not come out openly, lack self-confidence and feel like they are rejected in the society and they do not disclose, they do not come out to stand for posts because they feel they are not the right people. They blame themselves. (28-year old female Key Informant, KI 09)*

### 5.4 Dynamics of seeking behavior

Generally, from the study were found issues of poor public awareness and low willingness to seek treatment, as well as stigma against mental related problems. There could be a lack of motivation and knowledge to seek out treatment but also pressure from families, and drug costs could play a role. Other barriers to treatment were family, community and individual attitudes, contributing to the burden of disease and a lack of help-seeking behavior. On investigating the type of seeking behavior that YLHIV exhibited, it was established that to some, it was voluntary; others were encouraged by their parents. Voluntary counseling and Testing (VCT) was identified as an effective tool in reducing HIV transmission. It has been shown to provide behavior change and emotional support for those who test positive for HIV and to be feasible and acceptable in reducing perinatal transmission of the virus. During the in-depth case study, two participants, with the first one at Naguru Teenage center, indicated that they were not ready for voluntary testing.

The Naguru case said he was not ready for voluntary HIV and AIDS testing until it came to a point when he was falling sick from time to time. The guardian advised him to go for testing. He testified



that he took the guardian with him all the time, until the guardian and the health workers consoled and counseled him. They have never stopped doing so. The informant and the guardian are not willing to disclose the problem to other people outside their family circles. They have continued to give care to their person. He added:

*I have learnt to live with it and I follow the instructions given by the medical workers. The guardian continues to remind me of the hospital appointments.*  
**(21- year old male participant, M016)**

It was revealed that the health workers gave good counseling services, although there were some who were rebuking their clients and giving them bad remarks. The other participant, from Nsambya Health Care Unit, revealed that she faced stigma but “life has to continue”. Therefore, she had to accept to go for treatment. The worries of not continuing with her studies and not getting an heir remain prevalent in her mind. She is under the care of her aunt, who does not want neighbors and other people to know her status. The level of confidentiality was very high. She further expressed her worries: “I am on drugs but do not want people to know”, the informant revealed. Furthermore, she revealed that the stigma reduced after being counseled and advised by medical experts.

## **5.5 Parental decision**

Parents identified as one of the key stakeholders in the implementation of the proposal to prevent HIV and AIDS among the youth. Several participants cited the need to involve parents as part of the comprehensive strategy for improving youth health and development and prevention of HIV and AIDS. It was reported that this advocacy relies on the assumption that parents are knowledgeable enough to teach their children about sexual topics, including HIV and AIDS. However, during the study, there was little or no evidence to prove that parents are knowledgeable enough and fully equipped to teach their children about HIV and AIDS.

This lack of evidence shows that parents are an understudied and underutilized resource in HIV and AIDS interventions, particularly in Uganda. It was reported that some youth are not willing to test for their HIV status but their parents force them. The unwillingness to go for testing was not supported by the two in Focus Group Discussions, compared to those who were willing. It was

reported that the relatives or family members also try to hide HIV and AIDS patients by creating other diseases. One of the participants explained:

*The common reports given are so and so is suffering from cancer, hepatitis B, or most likely ulcers. Others go ahead and note that my child is suffering from an unknown disease. We have toured all hospitals but they have not detected the disease. (36- year old female Key Informant, KI 01)*

The key participants were teachers, parents/guardians and health workers. Teachers agreed that HIV non- disclosure of HIV status affects HIV and AIDS treatment- seeking behavior in such a way that they fear to go for HIV testing because they dread being known by their friends, in case results come out as positive. They feel the status can cause rejection by their peers.

It was reported from the study that the different types of care and treatment provided by the centers are ARV tablets, treatment for other diseases like cough and counseling services. All these services were provided by hospitals and health centers particularly for the youth. In Nsambya, it was revealed that they also make follow-ups for their patients and give lots of drinks and eats. It was established that they do counseling before you are tested, so that if a positive result comes out, you are already aware of what to do to live a positive life and you get a chance to chat with other fellow youth, and share experiences and encouragement.

Our study suggests that, although most youth are aware of its nature and how they acquired HIV, there were still significant gaps in the awareness of HIV risk factors and some of the specifics related to viral and immunological responses to HIV. The lack of appropriate information has been reported in other studies of youth transitioning into adult care (Landefeld et al., 2018b; Reis et al., 2021).

## **5.6 Discussion of study findings**

In this study, data collected using interviews with the youth living with HIV, AIDS on the nature of HIV treatment-seeking behavior among the youth living with HIV in Kampala City, HIV related barriers, and facilitators that prevent the youth from seeking HIV related services in Kampala as perceived and experienced by YLWHA. It was revealed that treatment seeking was not a common practice, upon confirming the positive status of HIV and AIDS. Fear of rejection, lack of disclosure, denial and being seronegative, belief in witchcraft and spiritual beliefs were barriers

identified at individual level. However, following a delay in seeking for treatment, a few factors that brought a positive turnaround included: at providers' level, support and good patient-staff relationship facilitated linkage, while negative attitudes and abusive language were reported barriers to successful linkage. Clear referral procedures and well-organized clinic procedures that are systematically used at the level of facilitators, whereas poorly organized clinic procedures and visit schedules, overcrowding, long waiting times and lack of resources were reported barriers.

According to Dow et al., (2020), hospitals assist uninfected individuals in assessing their personal risk and adopting risk reduction behaviors as well as strengthening prevention efforts, particularly at the community level. Factors positively related to HIV testing in the Republic of South Africa include older age, greater education, greater HIV knowledge, higher risk perception, and knowing someone with HIV (Bonnington et al., 2017b; Ndidi, 2012). The actual uptake in most of Sub-Saharan Africa remains quite low, despite the utility of VCT (Bavel et al., 2020; Muwanguzi et al., 2019). It is estimated that only about 45% of people living with HIV in Sub-Saharan Africa know their status (Nakanwagi et al., 2016b).

From the interviews, I realized that most YLHIV seek treatment from hospitals. The accessibility to services, information and educational initiatives concerning HIV and AIDS does not guarantee access of a person to proper treatment. Health-seeking behavior of an individual determines their approach towards receiving proper treatment for a disease. Research on cultural aspects supports the importance of knowledge regarding the disease and the health-seeking behavior of patients. Other significant factors related to the HIV-infected person and their access to treatment reported in the study were lack of information, prejudice and an unsupportive attitude of healthcare providers, unavailability of a patient's medical history/reports from previous consultations, legal status and use of traditional medicine(Dow et al., 2020b; Kalichman & Simbayi, 2003; Kimera et al., 2019a; Oskouie et al., 2017).

It was established from the study that for PLHIV, the relationship between geographic distance and healthcare access is less clear. Distant health centers will not attract PLHIV to get services from them. It was found that though PLHIV often faces large economic, social and geographic barriers to accessing healthcare, in some instances, PLHIV might go farther than necessary for care. The reasons why PLHIV may travel the additional distance for care were not well described.

Fear of rejectionization, should they be seen and recognized by members of their community, was one explanation for why they travel farther.

The findings are supported by (Kimera et al., 2021; Molloy et al., 2020; Swahn et al., 2019a; Wachinger et al., 2021) who assert that studies do not account for the broad array of the source, types and functions of social support for PLHIV. Assessing social support from multiple sources in the social network is critical in the understanding of its impact in populations like youth living with HIV and AIDS (Dorsey et al., 2020; Dow et al., 2020; Haberer et al., 2017; Kimera et al., 2019b; Liu et al., 2020). As individuals born in rural areas acculturate and create several social interactions within their own local communities as well as to the hosting communities, their perceived level of social support may vary across distinct groups with which they interact. Thus, youths living with HIV and AIDS fear being stigmatized and losing their social support if their HIV status becomes known may be higher in the context of their own respective communities than the general community if the stigma attached to HIV infection is higher in the local communities of their own origin (Bourne et al., 2017; Poteat et al., 2021a; Swahn et al., 2019b) al., 2019).

Some study findings indicate the rate at which the youth make use of their services is still wanting as indicated by the participants. It was reported during the study that the level of utilization of health services is low when considered with the rate of HIV spread. This was attributed to the fact that youth, other people do not want to test for HIV, and AIDS due to the perceived fear of rejection challenges. It was established that most youth do not want to be seen at health centers and hospitals for fear of community rejection. This had lowered the rate of utilizing services related to HIV and AIDS. This was expressed in the interviews as one of the participants explained.

The above views are shared by (Akutukwasa et al., 2021; Nakanwagi et al., 2016a; Swann, 2018; Tattsbridge et al., 2020). Who examined whether the four stigma manifestations - enacted (discrimination), vicarious (hearing stories of discrimination), felt normative (perceptions of stigma's prevalence), and internalized (personal endorsement of stigma beliefs) - were linked with delays in seeking care among HIV-infected people in India. They conducted a cross-sectional survey among 961 HIV-positive men and women in Mumbai and Bengaluru (Rudolph et al., 2021). The study outcomes showed that enacted and internalized stigmas correlated with delays in seeking care after testing HIV-positive. The study concluded that developing stigma reduction intervention is vital to ensuring timely receipt of care.

Although youth participants in these interviews referred to the importance of HIV testing, actual experiences with HIV treatment and care, there was a perception that testing was only necessary for people with symptoms and signs of AIDS. These perceptions about voluntary counseling and testing are in contrast to actual testing experiences among the youth in other African countries.

For example, research carried out in Uganda and Kenya reflected similar views. However, the youth said that knowing one's status generally was the reason for testing rather than showing symptoms of disease.

Testing during advanced HIV infection creates the perception that HIV testing always results in a positive diagnosis and may contribute to the perception that finding out one's status speeds one's death. This brings about increased stigma and fear of HIV testing and perpetuates the belief that healthy-looking individuals cannot be HIV positive. Research in South Africa has repeatedly shown that young people have low levels of perceived HIV risk (Ajayi et al., 2020b; Elul et al., 2017; Erena et al., 2019; Kennedy et al., 2020). The perception that VCT is for the ill may be a manifestation of the inability of young people to accurately assess their risk of HIV infection.

Negative perceptions of health care professionals working in VCT and reproductive health are consistent with themes in the available literature from developed and developing countries (Ajayi et al., 2021; Dow et al., 2020b; Kalichman et al., 2021; Ogunbajo et al., 2017). Youth in four American cities noted that the attitudes of health care professionals heightened their anxiety about testing and stated that they found risk assessment questions embarrassingly personal and intrusive (Omotoso, 2021). Kenyan and Ugandan youth most commonly indicated that they desired a "kind" person to conduct Voluntary Counseling and Testing (Derose et al., 2017; Kalichman et al., 2021; Ogunbajo et al., 2017).

Erena et al., (2019) suggested that counseling that is more appropriate would increase the rate of youth return for posttest services. It appears from discussions with these South African youths that they too would like VCT testing and counseling to be conducted with sensitivity and kindness in a less medical model than is currently being used (Ensor et al., 2019).

Another study reported that the persons that youth disclosed to were supportive and responded positively, suggesting that young people may disclose to individuals within their network who they expect to be supportive (Feinstein, 2018; Ogunbajo et al., 2017). Studies from the United States

showed that adolescents are most likely to disclose to parents rather than sexual partners (Poteat, 2019; Vazifekhorani et al., 2018). In South Africa, there were reported fears of rejection, gossip, and discrimination among HIV-positive women disclosing to partners, but they also indicated that disclosure is more common in partnerships characterized as loving and trusting (Dow et al., 2020; Nakanwagi et al., 2016). Youth participants in this study were afraid of all these factors; moreover, they were concerned about partner violence, abandonment, sexual abstinence, and losing opportunities for marriage and children. It has been suggested that couples counseling can be highly effective in overcoming problems associated with sharing test results and issues of blame (Ensor et al., 2019; Nakanwagi et al., 2016). Youth participants in this study highlighted their preference for couples counseling to overcome many of their perceived obstacles to partner disclosure.

Fears about the social consequences of HIV infection, particularly stigma, appeared to be significant barriers to accessing VCT. The participants mentioned stigma-associated factors such as stereotyping, separation, status loss, and discrimination as reasons for avoiding testing. Stigma from community members was particularly significant for participants and reflected in the fact that no mention was made of community care and support for HIV-infected individuals. The recurring mention of suicide and continued risk behaviors after a negative diagnosis are important dynamics to consider in the provision of VCT for the youth in Uganda. Programs must ensure that they maintain vigilance around these issues and have sufficient care, support, and referral services in place to assist HIV-infected youth to manage depression and anxiety and that uninfected youth are adequately counseled on maintaining safe sexual behavior through their changing sexual relationships (Erena et al., 2019; Kusemererwa et al., 2021; Oskouie et al., 2017). Whether access to treatment reduces barriers to treatment, including stigma (through reducing fear of imminent death) and increases sexual risk taking, are questions that have begun to be studied in the context of developing countries. However, there is no recent literature on this topic for developing countries.

It is pertinent to recognize that the youth in Uganda are not a homogeneous group. Their experiences vary according to many factors, including cultural background, tribes, gender, socioeconomic status, and educational background. For many, the stigma they face in relation to their sexual and reproductive health intersect during their daily lives with other kinds of stigma

derived from different forms of social inequality (Poteat et al., 2021; Rudolph et al., 2021; Wachinger et al., 2021; Yang et al., 2007). For example, a young unemployed man having sex with other men in a low-income urban neighborhood is likely to experience stigma from a variety of sources. Therefore, tackling stigma requires addressing its underlying causes.

Research suggests these causes are consistent across different contexts and include lack of awareness of stigma and its damaging effects; fear of acquiring HIV through everyday contact; and values linking people with HIV to behavior considered improper and immoral (Bonnington et al., 2017; Swann, 2018). “The drivers of stigma can be addressed with any target group. By creating awareness of what stigma is and why it is beneficial to reduce it, fostering motivation for change; addressing fears and misconceptions about transmission of HIV. Discussing “taboo” topics that are linked to and fuel HIV stigma and discrimination, such as gender, violence, sexuality and injecting drug use; and providing the skills to challenge stigma and to change behavior” (Liu et al., 2020; Nakanwagi et al., 2016).

The above findings and discussions are aligned and premised on the Cognitive Behavioral Model (Beck, 1986), which helps describe to clients how a person’s thoughts and feelings interact, and eventually result in a behavior. CBT requires that clients have a strong understanding of the model that the theory is based upon, and the use of this visual guide will help you achieve that goal. In line with the Cognitive Behavioral Model, it is theorized in this study that youths’ cognitions about stigma attached with HIV and AIDS treatment greatly determine the extent to which they would seek HIV and AIDS treatment-seeking behaviors. Negative cognitions about stigma attached to HIV treatment would imply that they would not seek this treatment and positive behaviors would mean that stigma that people hold about HIV treatment-seeking behaviors would be eroded from youths (Gu et al., 2021; Li et al., 2017; Loutfy et al., 2012).

Voluntary Counseling and Testing (VCT) was identified as an effective tool in reducing HIV transmission. It was shown to provide behavior change and emotional support for those who test positive for HIV and to be feasible and acceptable in reducing perinatal transmission of the virus.

The findings are corroborated by (Wamoyi, 2020; Kimera et al., 2019; Ogunbajo et al., 2017; Vazifehkhori et al., 2018) studies among people living with HIV and AIDS in resource-limited setting in Ethiopia, which suggested that the experience of stigma and discrimination has an implication on care and support-seeking behavior (Kalichman & Simbayi, 2003; Kimera et al.,

2019). Findings also showed that the messages that were initially disseminated through mass media (e.g. radio and television) combined with limited effort to raise awareness within the community about the disease were identified as factors that affect the current level of stigma and discrimination (Wamoyi, 2020; Kimera et al., 2019; Ogunbajo et al., 2017).



## **CHAPTER SIX: EFFECT OF STIGMA ON YOUTHS' HIV TREATMENT SEEKING**

### **6.0 Introduction**

Many youths have been infected with human immunodeficiency virus (HIV) during the past four decades. The absence of effective HIV prevention and treatment efforts means that more people will be affected. Anticipate stigma and non-disclosure of HIV status are some of the greater enemies in the battle against HIV and acquired immunodeficiency syndrome (AIDS). Low HIV risk perception and HIV medication side effects are important factors that need to be addressed to create an effective response to HIV and AIDS prevention and treatment.

Study objective number three examined how stigma has affected the treatment-seeking behavior of youth living with HIV of 18 – 24 years old. A key research question asked was: “What role does HIV stigma play in influencing HIV treatment-seeking behavior among the youth in Kampala, in order to provide clarity and guidance about stigma and its roles”. In this chapter, I present the findings while placing particular emphasis on the following. The negative role that HIV and AIDS stigma plays among young people in relation to health seeking is manifested in various ways. For instance, HIV stigma generates negative energy, which results in self-isolation (which cuts off a person from receiving counsel from friends, obtaining support from peers, friends and seeking health services etc.). This explains how effective HIV treatment requires helpers who remind youth to swallow medicine; those that give youth emotional support, spiritually and emotional support is important to them. The Joint United Nations Programme on HIV and AIDS aims for HIV testing, treatment and viral suppression rates to be 95%--95%--95% by 2025. Patented drug prices remain a barrier to HIV treatment (Heath, et al, 2021).

The study findings revealed a depressing picture; whose fear of rejection and discrimination found to pervades their workplace, clinics and the community. Stigma and discrimination tend to be internalized by most of the youth living with HIV and AIDS and can cause serious problems on their respective emotional and physical wellbeing. This section presents major findings based on the in-depth individual and key participants' interviews.

Treatment seeking behavior among youths was analyzed following the guidelines:

Willingness to go for voluntary testing of HIV and AIDS by the youths

Willingness to disclose their status to other persons

Adherence to medical instructions as given by medical personnel

Interest that youths show in counseling services that are offered at different health units.

The in-depth case study, two participants a male and a female, participated in this case, one at Naguru Teenage center another one at Nsambya Mother Care. One was a male who gave the following information when asked whether he was willing to go for voluntary testing.

*He was not ready for voluntary HIV and AIDS until it came to a point when he was falling sick from time to time. The guardian advised him to go for testing. He testified that he was taken and the guardian was with him all the time until the guardian and the health workers consoled and counseled him. They have never stopped doing so.*

The participant and the guardian are not willing to disclose the problem to other people outside their family circles. They have continued to give care to their person. He added that:

*"I have learnt to live with it and I follow the instructions given by the medical workers".*

*The guardian continues to remind him of the hospital appointments.*

It was also revealed that the health workers gave good counseling services although there were some who were rebuking their clients and giving bad remarks. The female participant from the Health Care center revealed that she was stigmatized but she stated that:

*"Life has to continue". So she had to accept to go for treatment. The worries of not continuing with her studies and not getting "an heir" remain great in her mind.*

She is under the care of her aunt who does not want neighbors and other people to know her status. *The level of confidentiality was very high. "I am on drugs but do not want people to know".* The

informant revealed. Furthermore, she revealed that the stigma reduced after being counseled and advised by medical service providers.

The interviews that were carried out among twenty- two participants yielded the following observations in the table.

**Table 6-1: Showing reponses of in-depth interviews**

Observation	Counts
Avoiding voluntary testing	15
Forced to test at antenatal clinics	9
Mothers stop breast feeding their babies	7
Some do not want to use condoms	12
Going to health units where they are not known	11
Women going with “borrowed husbands” for antenatal services	8
Giving different names at health units as a way of hiding identity	10
Attempts to avoid lectures and counseling services	10
Husbands or wives not allowing their spouses to know their status	5

Source: *Research data*

The group of “borrowed husbands” was mentioned. That was when an HIV and AIDS positive woman who is pregnant and does not want her husband to know her HIV status, requests another man to take her to antenatal clinics, then the requested man poses as the husband. The expecting mother is expected to pay for that service. The “borrowed husband” has to appear at each visit. One of the female participants revealed, “Our marriage could easily break if my husband learns that I am HIV positive”. The next submission was that: “I got a boyfriend because I wanted

to have a child. I knew I was positive but my worry was to die without a child”. She added that she was happy to have a child who is negative. There was no mention of the boyfriend’s status.

The characteristics of the treatment seeking behavior shown by youths are shown in the table 6.3 as:

**Table 6-2: Showing the characteristics of the treatment seeking behavior among the youth**

Group	Observations
1	<ul style="list-style-type: none"> <li>• By wishing not to meet people known to them as they go for health units</li> <li>• Avoiding to take drugs in the open/public</li> <li>• Hiding drugs</li> </ul>
2	<ul style="list-style-type: none"> <li>• Putting drugs in different containers</li> <li>• Avoiding to let school administrators know. Only deal with nurse</li> </ul>
3	<ul style="list-style-type: none"> <li>• Refusal to stop drinking/taking alcohol when they are on ARVs</li> <li>• Taking alcohols with the hope of overcoming psychological torture</li> </ul>
4	<ul style="list-style-type: none"> <li>• Going to health center where they are not known</li> <li>• Bribing health workers in to giving different results; that the person is negative when he/she is positive</li> <li>• Avoiding to tell their employers</li> </ul>
5	<ul style="list-style-type: none"> <li>• Not adhering to medical advices</li> <li>• Avoiding to tell their spouses</li> <li>• Reporting different diseases to the public</li> <li>• Interest in giving birth to children</li> </ul>

**Source: Research data (FDGs)**

The key informants in this study were teachers, parents/guardians, and health workers, provided their submissions. Teachers agreed that HIV medication side effects affect HIV and AIDS treatment seeking behavior in such a way that:

*The fear to go for HIV and AIDS testing because they fear to be known by their friends, in case results come out as positive, they feel the status can cause rejection by their peers.*

*In schools and institutions, students prefer to deal with nurses instead of dealing with teachers and administrators.*

*Some youths fail to adhere to medical instructions*

*Some teachers behave unprofessionally and rebuke students in public. Students try to avoid such teachers.*

The parents/guardians revealed that:

*There are some youths who look as if they have forgotten the ways through which HIV and AIDS spreads, they behave in any way they want with the hope that they shall get consolation in that fashion. Instead of seeking treatment, they show signs of having given up life. Some have to be reminded of their appointments at health units, whereas there are some who respond positively.*

With health workers, it was revealed that:

*Some show poor adherence to medical instructions and recommendations, others show adherence. Appointments are not sometimes followed, some have to be reminded on phones. They at times feel embarrassed, when they have to start on ARVs. Sometimes little interest in counseling sessions is shown. They fear some health workers who give negative comments towards them.*

Several participants reported experiencing discrimination in both work places and home environments. At work places, co-workers and managers perpetuated stigma as is indicated by the following:

*I do not want them (colleagues) to gossip and me about me (Male participant, 19 years). At first, when I took those medications I was in boarding school. I was coughing all the time, some colleagues were laughing at me, and I felt bad. I do not know how the manager in my department got to know but he knew and told them. They gossiped against (back bitted) me whenever I passed (Female participant, 23old years)*

The youth described HIV and AIDS as 'Walumbe', slim, Kawuka, and Kavera, which literally mean death, slim, virus, and polythene paper, respectively. The responses show that HIV and AIDS is commonly associated with death. The issue is that there is no cure; therefore, it leads to death any time. Furthermore, HIV and AIDS is associated with fornication, prostitution, adultery or

extramarital sexual relationships. “The public opinion is always negative” according to the participants”. It becomes shocking to get news that so and so is HIV and AIDS positive. In one participant’s words:

*Public sees the sero-status as being promiscuous, being a mobile grave – a nick name given to a person who may die any time, fear of not being employed especially when their jobs in place like United Arab Emirates (AUE). (Female participant 18 year old)*

When asked about the barriers to HIV treatment-seeking behavior, the two of the youth agreed that low HIV risk perception affects HIV and AIDS treatment-seeking behavior among the youth. One view is seen below.

*They fear to go for HIV and AIDS testing because they fear to be known by their friends. In case results come out positive, they feel the status can cause rejection by their peers. In schools and institutions, students prefer to deal with nurses instead of dealing with teachers and administrators. ... Some teachers behave unprofessionally and rebuke students in public. Students try to avoid such teachers.*

## **6.1 Isolation**

The participants said that isolation is the predominant reaction to HIV. Stigma is used to marginalize and exclude youth who are living with HIV and AIDS. Cautiousness from fear of infection also leads people to prevent their children from having contact with those known to be living with HIV and AIDS. In addition, some family members of those living with HIV and AIDS try to prevent them from doing casual housework such as preparing food for the family. If a person has HIV, it is assumed the person is already dead; therefore, they cannot take part in any decision-making process of the family. Unfortunately, specific eating utensils were designated to those living with HIV when their families discovered that they were HIV positive; this isolate and makes youth living with HIV and AIDS very vulnerable. Apart from stigma related issues, the following question was put to the study participants:

Are you satisfied with HIV treatment and care services for youth in your community? If not, would you share the reasons why?

It was revealed that the youth were provided with integrated psychosocial support and clinical care, including ART delivery. Some of the youth were able to obtain the health services they needed and some youth easily accessed the available services. To some youth, health services were provided in ways that meet their expectations including sensitive and non-judgmental health providers. The right, age-sensitive health services that the youth need were provided and the right health services were obtained in the best way and made a positive contribution to the health of the youth.

#### **6.1.1 Labeling, insults with various names and gossip**

Gossip, verbal harassment or ridicule and ostracism toward people living with HIV were highlighted as is seen below.

*People living with HIV have particular fears about disclosure and knowing whom to trust. There is silence around HIV because of gossip and labeling. (Male participants 22- year -old)*

The participants reported that it was important for them to test for HIV; however, they were afraid of what would happen to them thereafter. Therefore, this fear of “what might happen” acted as a barrier to testing.

#### **6.2 Beliefs and testing**

Participants in all individual interviews highlighted the need for youth to “know their status.” One said:

*Nowadays, it is important to know your status; I think they must go and get tested because you may think that you are negative whilst you are not. (Female participant 21-year-old)*

Despite this belief, it was reported that few participants had personally been through the counseling and testing process and knew their HIV status. A single female participant reported having wanted her boyfriend to accompany her for testing, but he refused. Three young men reported having tested for HIV as part of routine testing and counseling for recruitment to join the army.

### **6.2.1 Behavior after testing negative or positive**

Findings indicated that youth might not change their sexual behavior upon learning their HIV status. For example, a negative diagnosis would give youth the false confidence that they can engage in high-risk behavior and “get away with it.” Some young people perceived an HIV-negative diagnosis as a reason for celebration with relatively little thought about future sexual behavior and amelioration of risk (behavioral reactions to an HIV-negative diagnosis - celebration without behavior change).

*According to me, when he finds out that he is negative, he will continue with the past actions he used to do and thinking there is no such thing as HIV and AIDS.  
(Female participant, 23 year old)*

A small number of participants were well informed about issues such as the window period and were aware of the need to test again if one had had unprotected sex (behavioral reactions to an HIV-negative diagnosis - behavior change). They warned other youths about the potential need for testing again to make sure that their negative results were accurate.

### **6.2.2 Testing as a remedy**

Participants were less likely to discuss changes to sexual behavior after a positive diagnosis than they were to discuss the social ramifications of HIV infection. A small number of participants discussed the need to change sexual behavior, especially through condom use or abstinence. Interestingly, a number of participants indicated that knowing one’s HIV status would encourage them to become involved in HIV health services and care. This is what one participant said:

*Someone’s behavior will change in a positive way. S/he will start to be more responsible about his/her sexual lifestyle, and use protection every time s/he has sex. He or she will start to educate his/her parents, friends, and the community about the virus, and particularly his/her peers who are ignorant about HIV and AIDS. (Female participant 19 year old)*

### **6.2.3 Disclosure**

Some participants had a feeling that they would disclose to parents and/or family members before any other group or friends. They indicated that being HIV-positive is a disgrace to the family and



the community; although parents and family members might be angry, they would offer support and could be trusted to keep results a secret from others, as is seen below

*The family is better for disclosure because they can keep that thing within the family. (Male participant)*

A few participants feared the *ongoing* negative consequences of disclosing to parents or relatives that would not be resolved. One of them said:

*A father or a relative would not understand. He/she will ask how I got this sickness. He/she will even call me Satan. I think he/she would even chase me away from the house. He will not care where I go. Even the aunt/mother would be a lion (furious). (Female participant 23 year old)*

The study revealed that friends were the next most popular group to disclose to; however, youth expressed greater reservations about disclosing to close friends compared to family members. Friends were considered important because they provided a shoulder to lean on. Nevertheless, there were some worries that some friends might disclose their HIV status results to others, which would result in gossip that is more harmful than the potential emotional support from a friend. One view is seen below.

*I think that he will go to a friend instead of any family member because he will need someone who can comfort him...Therefore, the friend will be the only person he will tell. A best friend will advise him to do something about his health. (Female participant)*

Partners were the least mentioned with regard to disclosure. To the participants such disclosure was problematic because discovering one's HIV-seropositive status has implications for a sexual relationship, particularly with regard to issues of trust and blame. Disclosure to partners was seen as a significant source of anxiety. Although some participants acknowledged that disclosing to family and friends had the potential for rejection and discrimination, they also perceived it as potentially carrying additional consequences of abandonment and loss of potential for marriage and children. One male participant illustrated this as follows:

*There is a higher risk involved for me to go for testing because my girlfriend might leave me to face the situation alone if I test HIV positive....If I were positive and she's negative, that means she is going to dump me and look for a better one who is HIV negative .... I would be alone.*

Most of the participants agreed to the idea of counseling as a potential solution to getting tested and disclosing results to partners.

### **6.3 Family care and support**

The parents indicated that they would need to be a resource for their HIV-positive children. However, they questioned their abilities to provide this care and noted that they would also need counseling to assist them in accepting, coping, and caring for positive children.

Results from FGDs and in – depth interviews were integrated because the same themes were derived from both data sources and reported together. The participants narrated that treatment delays compromise health and increase the risk of transmission to others. The themes of stigma that resulted from data were analyzed, to find out whether they influenced treatment-seeking behavior among the youth.

#### **6.3.1 Psychological and social effects of stigma**

From the findings, I realized that culture contributes to stigma, and cultural beliefs about HIV. This also helped to answer the research question “What role does HIV stigma play in influencing HIV treatment-seeking behavior among the youth living with HIV in Kampala City?”

Looking at women as inferiors, culturally contributes to stigma. The most frequently occurring theme under this topic referred to the participants feeling that culture contributes to HIV – related stigma in fourteen interviews mentioned. One of the female interviewees aged 19 years F010 said:

*“It is getting worse because of our cultural beliefs”.*

*‘The cultural practices in our community norms worsen the faith of women living with HIV and AIDS, they used to call us all sorts of names and disregard us in many normal daily activities, avoiding any close associations with most of us. But I found strength in coming to this mother Care facility where I could at least mingle and interact with others of the same faith as I am.....’.*

Participant (M01) eighteen years old explained,

*“They are not well enlightened about HIV. It is making it worse because of our cultural beliefs.”*

Participant (F06) twenty - one years old prescribed,

*“It is making it worse because of our cultural beliefs”.*

Participant (M07) twenty-three years old mentioned,

*“It is making it worse because of our cultural norms, morals and beliefs in the society”.*

Participant (F09) twenty-one years old described,

*“The culture makes it bad, and they put the blame on both of us”.*

#### **6.4 Effect of stigma on HIV treatment-seeking behavior**

The participants cited HIV-related perceived stigma during the study to influence HIV treatment-seeking behavior. Participants during the interviews, Focus Group Discussions and case studies with youth living with HIV, expressed different ways in which this effect their treatment-seeking behavior. It was found that numerous social issues arise due to stigma on PLHIV. It is indisputable that mental health is the primary requirement for good health, and the main impetus of the wellbeing of youth LHIV. Unfortunately, it was found out that PLHIV living with HIV-AIDS are quite often stigmatized; a stigma that persists to this day. Participants revealed that this process fills them with feelings of shame and guilt, feelings that definitely do not help them maintain high self-esteem and a healthy mental state. The youth living with HIV, face depressing and suicidal thoughts, in their respective communities as HIV-related stigma and discrimination govern their lives and hinder them from seeking treatment. One of the participants observed:

*When the youth has no one to care for him and give him courage to go on with life despite the infection with HIV and AIDS’ it hurts. ‘People don’t want to share openly with such people because they will say those are utensils for the other person. Don’t use them’ (23-year old male key informant, KI 06)*

The university participant described her lived experience in learning environments:

*“At an institution when you have HIV you don’t enjoy it like other children because you know you have HIV and you fear that they will find out. So, you stay alone unless you have a friend also with HIV in the same school” (21-year-old female in an institution).*

Many youth viewed themselves as worthless and similarly other people took the same stance about them. Some YLWHA believed that HIV precluded them from studying and progressing academically like other HIV-negative peers, and as a result, they refused to enroll or stay in school and above all, they fear to seek HIV treatment.

The participants mentioned friends, families and community awareness as one of the most humiliating experiences. At school, fellow students may not want to share plates, bedding or even when he passes by, students start back-biting him or her about his or her HIV status and also keeping a distance from him or her; in other words isolating him or her.

Another participant observed:

*Such non- disclosure of HIV status affects treatment seeking care as they feel self-pity and keep a low profile (Bekubagiza) something that makes them not to go for treatment from health care centers, they hide, they don’t disclose and I think they feel they are giving you hard time and I think some have “entondo” they can’t disclose openly. (34-year old female teacher, KI 07)*

## **6.5 Effects of self- stigma HIV treatment-seeking behavior**

It was reported that due to stigma, individuals reduced their social interactions with members of the community. They tried to conceal their illness. One of the participants explained:

*“After finding out my HIV and AIDS infection, I stopped interacting with my friends, not to let them know about my condition and have wrong judgment about me.” He adds “I like to receive services from AIDS patients’ club (AIDS club), which is found near the clinical center but I am afraid of being known by students or colleagues; so I do not take part in club programs”. (23- year old female participant, Group 03)*

Some youth noted cases where they had been discriminated against by others at different institutions and circumstances where they considered weak and not fit to participate in activities like sports and games. One 19-year-old male narrated how a teacher stopped him from playing football because he was 'sick' (had HIV). This caused him to feel excluded from the rest of the students. Three female participants further said that it affected them when others taunted them that they are sick or on treatment or have a virus. Such statements often excluded them from possibilities of participating in school activities. In the words of one of them:

*“Discriminating me is the worst thing that has really disturbed me. Like pointing at me every time and even telling me that I am sick continuously by teachers and students, yet I know that I am sick” (19- year-old female in a day Vocational School).*

Isolation of YLWHA is normally done for fear that they would infect others. The youth reported that such fears occurred due to ignorance of others about ways in which HIV is transmitted. A few female participants reported that others isolated them because they did not trust them. According to these participants, other HIV negative peers at school thought that they could deliberately transmit the virus to them. Because of these attitudes and behaviors, many YLWHA concealed their status at school and isolated themselves from others, for fear of their status being known and causing them to feel different from the others. However, inadvertent status disclosure is reported to occur, especially in residential institutions due to living with many peers for a long time and due to the indiscretion of teachers, school nurses and matrons that some YLWHA would trust to disclose to them. This breach of trust always left YLWHA muzzled and unhappy at institutions.

The in-depth case study of the two participants revealed as: Male participant in Naguru Teenage Home responded, *“Life has to continue and I have to get used to HIV and AIDs. I have to accept that I have it.”* The ways that participant was following included accepting the advice given by health workers, visiting health units on appointed times, following precautions that were given from time to time, doing her work normally as if there is nothing wrong and remaining content with the services that were offered at the health unit.

A female participant in Nsambya Health Care Home responded that:

*“I feel better with the medical services I am receiving; signs have disappeared since I received treatment”.*

She admitted that services were good, for she was receiving drugs and food rations. Health workers were very caring, too; they gave her good counsel. Her guardians showed great care, close friends were friendly and caring and the pastors in the church are always giving words of hope.

### **6.6 Perceived effect of Poverty**

Although stigma has its role to play, there are factors that were identified to have an effect on treatment seeking. These include distance, poverty and others. The location of health centers in distant places resulted in difficulty of YLWHIV and their families going to a hospital for care. In addition to that, difficulty in traveling to apply for welfare grants meant for YLWHIV, seeing as many youths are unable to pay for transportation and user fees for healthcare services, makes it a clear indicator that poor YLWHIV will not obtain adequate care services. Even in cases where drugs are freely available, fear of taking medications on an empty stomach discourages them. One of the participants mentioned this:

*When I do not have what to eat or I do not take my drug, they will not work well.*  
*(22- year old Male participant, M002)*

### **6.7 Sharing experiences about taking ARVs in support groups**

Social support is a psychological aspect that helps groups that seem to play an important role in handling stigma and discrimination. Such groups constitute a platform for learning about challenges related to living with HIV and taking ARVs.

The following quote describes this:

*We always have conversations with my fellow support group members about different difficulties related to adhere to ARVs and how to cope. In this way, we console and comfort each other. We meet weekly in our support group. Also, my husband comforts me. He is a medical personnel so he knows these things well. (23 years old female participant, F004)*

It is noteworthy that the increased access of antiretroviral therapy that some youth mentioned could be one of the reasons for them to be positive about their health condition as is indicated below.

*“Now there is ARVs treatment that helps us to decrease the viral load and increase our cd-4 counts (21 years old male participant, M010)”.*

*“It is better now because there is ARVs treatment (Participant F003, Group 4)”.*

*“I am also on ARVs and not scared to disclose my status because if I do not disclose I will die of stress and find it difficult to get treatment (20 years old female participant, F005)”.*

Critical analysis of the above and other statements provided by participants demonstrates that some youth behave differently; there are some youth who are not challenged by stigma; and some youth sought for treatment early.

## **6.8 Discussion of study findings**

The study sought to examine and understand the role HIV stigma plays in influencing HIV treatment-seeking behavior among the youths in Kampala. In this respect, research question three, asks the role HIV stigma plays in influencing HIV treatment-seeking behavior among the youth. The study findings revealed a significant burden to adhere to the highly treasured ART regimens while simultaneously maintaining secrecy of the sero-status that YLWHA grappled with. This seems to be uniquely so in school communities where they live and interact closely with people with divergent views on HIV and AIDS, and people living with it. YLWHA always had to weigh the risk of taking ART at school and the benefit of schooling. Since ART showed more immediate outcomes of improved health compared to schooling, they were always quick to disregard the latter. The key risks associated with taking ART at school as reported by participants were unintentional disclosure and subsequent discrimination. Although HIV and AIDS has been theorized as a concealable stigmatized identity, our findings show that within the school context YLWHA are highly noticeable. Both internalized and externalized overt and covert forms of HIV-related stigma are reported in this study. Our study reinforces findings from several other studies

on disclosure and medication adherence in YLWHA, reporting HIV-related stigma as a key hindrance in school.

Stigma and discrimination towards the youth living with HIV and AIDS is not a phenomenon unique for Ugandan society or other countries in Sub-Saharan Africa. Stigmatizing attitudes occur all over the world. However, expressions and consequences differ depending on social and economic contexts. In some countries, for example in Sweden, stigma and mainly fear of rejection is a major problem among people living with HIV and AIDS.

From experiences I had with the community of Positiva Gruppen Väst, common prejudice in Swedish society is that HIV and AIDS only affect injecting drug addicts and homosexual men. Furthermore, the staff members narrate at PG Väst that there are still misconceptions regarding how HIV is contracted, which contributes to an exaggerated fear or carefulness when being around an infected person. Many people have experienced bad treatment from staff members within medical services, especially when seeking assistance for other medical complaints. For example, it is common that people get questions about issues rather irrelevant for their complaint i.e. how they were infected.

However, a major difference is that people in welfare states like Sweden are dependent, economically and socially, on their families and most people are able to carry on with their lives even without accepting and understanding families. Similarly, the Cognitive Behavioral Model by Beck and Skinner (1986) could be applicable to gain an insight into understanding the perceptions and experiences of stigma. Stigma in this case is viewed as a cognitive aspect of human behavior. Beck and Skinner postulate that a person's cognitions influence behavior and vice versa. According to Beck and Skinner, cognition is a thought or a perception, a belief, a feeling, or a point of view. For example, someone who is afraid of embarrassment and believes that one will be embarrassed if one goes for HIV testing or treatment, will avoid it, for fear of being embarrassed.

Therefore, avoidance is the behavior that has resulted from the cognition, which also implies stigmatization. One implication of this cognitive behavioral model is that if the cognition altered the behavior alters too. This model expounds that people adapt strategies for dealing with stress; it is further influenced by the assumption that a given situation is controllable or changeable.



Therefore, to deal with the stress of a given situation, adaptive strategies are developed to match the situation, including the individual's conviction and attitudes to reality.

A fundamental component of coping process is seen as an appraisal by the person facing a stressful situation, which involves an evaluation of both the demands of the situation and the personal efforts the person can exert or exerts to deal with the situation (Demirtaş-Madran, 2020; Dias, et al., 2019). The researchers chose this theory as a tool or a lens to help in understanding the way participants deal with the situation. It is argued that self, enacted or perceived stigma is reality that exists and a deterrent to overcoming the HIV and AIDS epidemic, the obtaining of treatment is therefore, a goal for the individual's wellbeing.

Generally, stigma is described as a negative reaction to an attribute in an individual that is deemed as undesirable or discrediting in a social or societal setting (Chambers, Rueda, Baker, Wilson, Deutsch, Raeifar, Rourke, Adam, et al., 2015; Creswell et al., 2020; Muwanguzi et al., 2019a; Skovdal, 2019). It is compared to societal power structures when one group of individuals develops prejudicial thoughts and behaviors toward another group of individuals who share a particular attribute (Turan et al., 2016). In the context of HIV and AIDS, HIV and AIDS-related stigma consists of unfavorable attitudes, beliefs, and policies directed toward people perceived to have HIV and AIDS and toward their loved ones, associates, and communities (Deering et al., 2021a; Kooij et al., 2021; Reif et al., 2021). The youth who know their status and are able to access treatment experience several challenges: disclosure, stigma and discrimination, and lack of support to help them remain on treatment.

Finding optimal antiretroviral regimens and supporting improved clinical and social support and care can be critical to reducing AIDS-related deaths in the young generation, and this requires a holistic, life-cycle approach (Earnshaw et al., 2020; Obiri-Yeboah et al., 2016). All over the world, HIV and AIDS related stigma and discrimination are of growing concern. At the same time, self-stigma is one of the influential factors that make people living with HIV and AIDS (PLWHAs) feel ashamed and guilty about their positive status. Stigma has been largely ignored by the existing policies of some sub-Saharan countries (Deering et al., 2021b; Lazarus et al., 2021; Stutterheim et al., 2017). Stigma can deter or delay testing and disclosure. Nevertheless, in many countries

counseling is not taken as a crucial support for testing services and stimulated coping by denial and/or secrecy about their HIV status.

Stigma and discrimination act as impediments to the uptake of HIV testing, treatment and care and to adherence to treatment. A consistent, negative association has been found between fear of rejection (or perceived stigma) and use of testing and treatment services. However, it is unknown if decreased stigma causes increased uptake of services, or if increased access to testing and treatment causes stigma to fall. In Botswana, a survey of HIV patients on Antiretroviral Therapy (ART) found that 40 percent had delayed testing for HIV because of stigma (Harkness et al., 2021). Stigmatizing beliefs, which perpetuate the notion that HIV can also reduce the amounts of people testing, as people are less likely to believe they are at risk. Another study found that men with more stigmatizing attitudes were less likely to have had an HIV test (Quinn et al., 2019; S Rueda, 2016).

Stigma often prevents disclosure of an HIV-positive status to partners, providers and family members, who would deter behaviors that can further spread HIV, such as condom use, or mitigate its impact, such as care - seeking (Batchelder et al., 2021; Pollini et al., 2021). Therefore, this study explores the psychosocial, environmental and socio-cultural factors that influence HIV help-seeking behavior among the youth living with HIV. The notion of double stigma is thought to be an added burden that faces young populations in the Sub- Sahara, but many impact disparate cultural groups in various countries of Africa. In conclusion, young people living with HIV have special requirements, which are often unmet. Laws and policies, for example, those dealing with age of consent for services, can specifically exclude young people from accessing sexual health and HIV-related services, including age-appropriate sexuality and prevention information and, in many countries, HIV counseling and testing.

In conclusion, the ideal situation would be a sick person to seek medical assistance from medical experts. That is a person goes to a health unit, he or she is tested in the laboratory and results are known, then the sick person is treated up to the point of recovery. It could be said that the person behaves like that because there is a possibility of the diseases being curable. When it comes to HIV and AIDs, this scourge is associated with shame of prostitution, fornication, adultery and so on, at the same being aware that it is not curable. An individual knows about the social or religious

status in society or the family background. The treatment seeking behavior has to be adjusted accordingly. There could be a set of people, including youths, who fear to be told their HIV and AIDS status. There is even the opinion that “Some youths feel that they are safe when they do not go for HIV and AIDs testing”. In short, they are not prepared for un- desirable results that are being told that ‘you are positive’. The social disgrace associated with HIV and AIDS (Ki-moon op-ed, 2018) is great. It is so great that there are people who fear buying condoms from drug shops, yet they could need them. At the same time there, those who do not know how to use them and worse, they fear being told how to use them.

## **CHAPTER SEVEN: RESPONSES AND COPING MECHANISMS OF HIV STIGMATIZED YOUTHS**

### **7.0 Introduction**

This chapter focuses on the coping mechanisms and responses innovated by youth to facilitate them to hope and to live a positive life as they struggle to find meaningful life at their present situation; and how these mechanisms contribute to the persistence of HIV stigma. This chapter therefore, provides insights into youth's fears, hopes and disappointments, struggles and accomplishments as they strive to survive with challenges of HIV and AIDS related stigma.

The study objective four investigated responses and coping mechanisms of HIV stigmatized youth living with HIV in the age bracket of 18 – 24 years old, in Kampala. More specifically, the following research question was answered: How does HIV stigmatized youth respond to and cope with HIV stigma? Besides the barriers, participants identified indicators of their quality of life quality, which were clustered into practical support at school, from families/homes and community; counseling, encouragement and spirituality; individual coping strategies; hopes, dreams and opportunities for the future.

The objective sought to establish that the youth have stigma but they have to live. They have to work for their survival. It was for that matter that the participants responded according to the question about coping mechanisms. In this report, the young people/youths are those who were HIV and AIDs positive and receiving treatment in different health units.

The issue was that much as they want the problem to be known to themselves and their close relatives and friends, the effects it has on their bodies and lives remain real. They must have ways and methods they are applying to go through stigma and experience. The submission of the participants was recorded.

The in-depth case study of the two informants revealed as:

The male participant at Naguru teenage center responded that

*“Life has to continue and I have to get used to HIV and AIDs, I have to accept that I have it”.*

The ways that participant was following were:

*Accepting the advice given by health workers. Visiting health units on appointed times. Following precautions that are given from time to time. Doing my work normally as if there is nothing wrong. Remained contented with the services that were being offered at the health center.*

Female participant in Nsambya Mother Care responded that:

*“I feel better with the medical services I am receiving; signs have disappeared since I received treatment”.*

She accepted that:

*Services were good for she was receiving drugs and food rations. Health workers were very caring, they were giving good counsel. Her guardians were showing great care. The close friends were friendly and caring. The pastors in the church are always giving words of hope.*

The twenty youth participants who were interviewed in the study raised a number of ways they go through in order to make life continue:

**Table 7-1: Showing responses of coping mechanisms**

Responses and observations of participants	Counts
Employers do not stop us to work, so we have to work	15
Believe in divine power and accepting Jesus as our Savior	16
Believing and having confidence in ourselves	15
Having hope that the future is still bright	14
Continue to go for treatment and take medicine as instructed	18
Sharing information and experience with other patients. Support each other	16
Getting involved in community support groups	13
Listen to programs on radios or view and listen to T.V programs	16
Role of parents/guardians plus religious leaders remain vital	12
Looking for safe care when giving birth	10
We are receiving good services at health units	13
Most of the health workers provide good counsel after testing positive	15
We have hope in our children and so we have to work and support them	19
Need to love and serve each other	7

Source: *Research data (In- depth interviews)*

For the Focus Discussion Group (FDGs), they showed the response to and coping with the HIV stigma in the following ways:

**Table 7- 2: FGDs responses to coping with HIV stigma**

Group	Responses
One	Accepting God's power and some of us get saved. Appreciating the services offered in health units.
Two	An African desire to have children haunts especially mothers. They have to seek great medical care in order to produce safe children. Have to work for their children.
Three	Accepting the counselors' advice Following all medical instructions and taking drugs
Four	Remaining obedient to employers Encouraging and comforting our fellow patients
Five	Not losing hope in the future Making life meaningful

The key informants, who were the teachers, parents / guardians and Health workers, had the following to say:

Teachers showed the possibility of a youth continuing with his/her studies if there is positive living. They further submitted that those who adhere to medical instructions and take drugs were doing well.

*Teachers have to accept them as there are and avoid uttering embarrassing remarks.*

Parents/guardians:

*They were providing care to the affected youths*

*Encouraging and comforting them*

*Those on treatment were doing well*

Health workers:

*Encourage youths to adhere to instructions*

*Keep medical appointments*

*Behave professionally.*

## 7.1 Practical support at home, school and community

The youth who had selectively disclosed their status appreciated support from various stakeholders in the school community. Although it was a challenge identifying individuals to confide in, when such people were identified, they played a meaningful facilitative role for these youth in school. From school authorities, these youth received transport and school leave permits to attend their clinic appointments. Some teachers provided reminders and encouragement to adhere to medication. Teachers additionally provided remedial classes, offered special consideration in case of missed examinations and shared their food with YLWHA in some cases. One participant reported that family members assisted him to pick his medicine from the clinic while he was at school.

*“Also let us say I am in examinations, my sister picks drugs for me as well as my mother” (18-year-old female in a boarding school).*

Those who were or had been to boarding and day schools suggested that receiving ART for the whole school term and reducing waiting time at the ART clinic would redeem time to keep up with school activities. The youth mentioned several times that compassionate people came to their rescue and provided food and scholastic materials. These were notably friends at school who would share with them the little they had, school matrons who would share with them food and neighbors in the community who out of empathy would give them clothes, food and some money. They additionally appreciated a small financial contribution that was occasionally provided at the ART clinics to enable them meet transport fare. Several participants reported feeling different from their fellow youth due to their HIV status because of their illness and they also had to take medications to survive, and they had internalized negative stereotypes about HIV, as one of the indicated below:

*I feel different up to now, from other people. Someone who looks miserable without HIV is far better than a person who looks healthy with HIV. (Who told you?) It is how I know it and I believe it is true (Female participant, 20 old years) All participants expressed concern and fear of gossiping, teasing, ridicule, and loss of friendships if their HIV status were to be known.*

From the analysis of the interview conducted as part of the data assembly process on stigma and coping mechanisms, the participants identified and came up with two distinct coping strategies that covered the

seven major coping ways. The identified coping strategies were emotional coping strategies; isolation, engaging in destructive reactions, providing positive reassurance to self, engaging in physical activity) and problem focused (e.g. seeking social support and seeking spiritual guidance).

## **7.2 Problem-focused strategies**

Participants mentioned self-disclosure as being useful to normalize the therapeutic process during counseling. Results from key participants, FGDs and individual interviews were integrated because the same themes derived from both data sources and were thus reported together from the youth testimonies in their own views of how they actively cope to avoid and combat this stigma. The teasing, bullying and insulting in families and communities made some of them move from one health provider to another in quest for the conducive environment.

Many of the youth had previously experienced and reported their symptoms as fragmented and incomprehensible. Gaining an understanding of their own reactions and experiences was, therefore, an important component of the recovery process. One female participant, for example, experienced that the psycho-education provided in the stabilization group helped her comprehend, and thus manage, her trauma-related stigma:

*I have had these problems for three years. It has been a dark cloud. Something completely unwieldy, that I could not touch, that I did not manage to do anything about. Nevertheless, I had hoped ... I believe that I can make it go away if I get help. Now, after the stabilization group, it is no longer a cloud of things that I do not know what is. It is almost like building blocks. Moreover, on each one of them it says what it is. I know what things are now. It is almost as if, when I have gotten some blocks in the right position, it is like a jigsaw puzzle. Everything else falls into place. Now I know which pieces are still missing from my jigsaw. Moreover, it is such a wonderful feeling! (22-year-old participant, F008)*

The other male participant too experienced that knowledge about stigma - related symptoms changed the way he viewed himself and his symptoms:

*Well, I was not even aware that all these symptoms were symptoms, you see. Then to see that all these things are connected. You did not have huge problems. It was just one problem so you focus on that problem, right. It is more tiring, to put it that*



*way, if you, during the day, first have to fight away the anxiety, then stressed for a while, and then you must ... Compared to working on the reason you get all of this, see?*

Another participant stated thus:

*I think that we need to normalize ourselves in what we are doing. I intend to normalize my feelings and you know, I think this is more prevalent among the youth of today in these divisions. However, for any of us even if we go to clinics voluntarily, there is anxiety; there is this feeling of talking to a stranger opening up personal things*

Some youths' narratives testified that they have to be always on the move from one apartment to another, those who rent apartments. This portrays the need for many of these youth to break out of the realm of stigma, see themselves in a more positive modality, through seeking more valuing surroundings, and assimilate this in their self-value. Some youth emphasized that concealment of status warranted in social settings, to avoid undue attention and devaluing treatments that cause such negative thoughts and low self-value to emerge.

These approaches aim at seeking some type of solution, like seeking social support, finding a purpose or involving in behaviors that aimed at advancing the hope of persons with HIV and AIDS.

Some youth reported a positive perception that they have hope and accepted their HIV as narrated by one of them as follows:

*I did not think that I would die and had hoped that I would live longer. I have not given up hope and have lived with infection for seven years (22-year-old participant, F004)*

It was revealed through the in – depth interviews and Focus Group Discussions that some YLHIV resort to praying to console themselves. *“I always go to church on Sunday; when you are in the church there is away you feel your heart is so relieved. This happens mostly when they are preaching. My heart strengthens each time I go to church.”* One other of the participants explained:

*I thank God for my life. Ever since I tested HIV positive, I resorted to my prayers in my church at Miracle Centre Cathedral. I found good friends that appreciate my status and I am consoled that there is a giver and taker of life. I repented of all my wrongs and asked God to grant me new life. I always praise Him. (21 – year old male participant, M004)*

### **7.2.1 Spiritual Devotion**

Two participants indicated that their faith in God gave them courage to adhere to medication. They received spiritual and psychological support from the religious leaders. Spiritual devotion appeared to be a strong coping strategy among study participants as is seen here:

*“I pray to God every time, I take my medicine and I believe one day Jesus Christ will cure me.” (23 years old female participant, F009)*

The study revealed that participants’ belief in the healing power of God had better health outcomes as their belief reduced their self-stigma. Indeed, their level of faith in the healing power of God was so high that some thought that, even if they died, it would not be because of HIV; it would be God’s will. The following quote is illustrative of this:

*“I get comfort from my religion because God is the one who enables us to live. In general, I perceive AIDS as a common disease and AIDS does not necessarily cause death. You can sleep without being sick and still die. Therefore, I believe if I die, then it is God’s will and not AIDS. (21 years old female participant, F0016)*

### **7.2.2 Social support**

The HIV-positive youth indicated that they do get pre-test and post-test counseling in hospitals or in clinics to assist them with their test results and to handle the difficulties which they will face in living with HIV and AIDS. Similarly, after being diagnosed with HIV and AIDS, the youths go back to their families, who are responsible for much of their nursing and care, both in and out of hospital. The family is the source of caregiving for HIV-positive individuals. It is very influential in reducing stigma within the family, which is very hard to address effectively if the family is not supportive. Some also indicated that even at school, some of their friends are supportive, especially those who are also HIV-positive. The following statements supported this:

*My relatives have been of great help; at times call me and ask me how I feel, to find out the situation I am in. (18-year old male participant, M007)*

*My employer helps me a lot; he encourages me to take the medicine. (23-year old male participant, M009)*

*My friends who are HIV-positive too, give me advice on what I should do; that they were once like me, you have to do this to see that you live a positive life and leave doing this and that, so they give me good advice. (21-year old female participant F016).*

### **7.3 Emotional coping strategies**

This type referred to personal, social and religious measures that are used to alleviate HIV-related stress and to stabilize emotions as shown in the statements below:

*When I compare my life right from childhood and when I got to know about my status, I only think of living longer to disprove those that think I will not survive for so long. As well as doing what is right that will sustain my desire to live longer; for example, taking my medicine at the right prescribed time by the doctors. (Male Participant 20 years old, M005)*

*I just became extra careful with my life, so that I do not spread the disease to other people. I am not the only one infected and always have hope in life as long as I keep taking my medicine. (Male Participant, M011)*

*Thinking about the future of my children makes me swallow my tablets. I now think about myself as that girl who is going to fight so much to support herself and my child because I have a child. (Female participant F013)*

#### **7.3.1 Withdrawal from love relationships**

Some YLWHA have expressed concern about their love relationships that are losing value. Some indicated that their partners are HIV-negative and they fear to disclose to them about their status, lest they lose them, while others request their partners to go for HIV testing and they refuse. So they have decided to quit the relationships, since they do not want to infect others. This is seen in the following statement:

*I always have different men and all are HIV-negative, so they ask me for blood testing and I dodge them, sometimes leave the testing, and ask me to go and stay with them, which really hurts me as a person. In addition, I ask myself why me. (19-year old female participant F020)*

### **7.3.2 Engaging in destructive behaviors**

This refers to personal measures that are used to mitigate against HIV-related stress or conflicts and to stabilize emotions as reflected in the following statements:

*Sometimes I go to drink to try to forget the reality of dying daily, although the doctors tell us not to drink. (24-year- male participant M006)*

*I sometimes go to club and take alcohol just to forget about my HIV status. I have not told my employer because where I worked first when I told them that I am HIV-positive, they tried very hard to get rid of me. So, I decided not to disclose to my employers because I got to know what it means. (19 –year - old female participant M002)*

### **7.4 Coping Strategies adopted to deal with HIV and AIDS**

Key coping mechanisms that emerged from participants' narrations included spiritual devotion, acceptance of the illness, seeking information and/or exchanging views about the illness, preemptive disclosure, putting ART in an unlabeled envelope, and swallowing ARVs in the washroom (toilets).

The study participants accepted the condition of being HIV positive and considered HIV and AIDS as no longer fatal, particularly after they started ART and experienced a remarkable improvement in health. One of the participants shared his feelings as follows:

*I see HIV as any other disease and I do not think that I will die because of HIV. When I pass on, I will know it is God's will, not because of AIDS. If I were to die, I could have died when I was very sick those days. (18 years old female participant, F005)*

Another participant expressed a similar concern:

*My conscience has agreed to the problem so I regard it as just any other common disease. (23 - Years- old male participant, M006).*

The notion of regarding HIV and AIDS as an ordinary disease was internalized mainly by the participants who were on ART for three years or more. Some participants spoke of the support they received from their families as having contributed to the peace of mind they were experiencing.

#### **7.4.1 Sharing Experiences and Support Groups**

Social support groups seemed to play an important role in handling stigma and discrimination in our respective communities. Such groups constitute a forum for learning about challenges related to living with HIV and taking ARVs.

The following quote is illustrative of this:

*'We discuss with my fellow support group members different challenges related to taking ARVs and how to cope. In this way, we console and comfort each other. We meet weekly in our support groups. In addition, my husband consoles me. She is a hospital employee so she knows these things well.'* (22-Year- old male participant, M003)

#### **7.4.2 Disclosure**

Some youth on drugs disclose their HIV status to family members, neighbors, and/or work colleagues and talk very freely about it and the challenges they face, so preempting gossip. This coping mechanism is narrated by one of the participants:

*'I have disclosed my status to almost everybody because I am sometimes seen on the television or heard on the radio revealing that I am HIV positive (I am an AIDS activist). At my workplace (vendor on streets of Kampala), everybody knows I am infected. It helped me a lot to disclose my status because I sometimes feel unable to work and I just tell my boss by phone that I am sick. She always understands the situation and my colleagues say jokingly "mmmh! Today viruses have woken up and are harassing her (in local language – akawuka kaludde)" that is why she was not able to report to work. One day, one of my colleagues told me that some of my*

*workmates were saying that I did not come yesterday because viruses were harassing me, but I just told her, I don't care (she laughs). (24-year-old female participant, F019)*

People of this kind, who disclose and talk freely about their HIV status, can strengthen others living with HIV by helping them overcome internalized stigma, cope with stigma, rebuild their self-esteem, and develop skills to take leadership roles in anti-stigma education and action.

Some youth emphasized that to overcome the negative societal views and an attitude, their individual effort is necessary. They experienced how openness about their status denied rumors, gossip room, and instilled a sparkle of change in their social environment. They additionally called upon others in the fight against HIV-related stigma to sensitize communities with correct information in public places such as schools and worship centers. Others pursued to be a role model for peers with HIV in their community. In further exploring the meaning of this activism, we understood that participants sought a meaningful role for themselves in relation to others with HIV and to their community, which was a significant source for retaining or regaining self-value (Anderson-Carpenter, 2021; Hightow-Weidman, 2017; Partow et al., 2021).

As another way of improving that, participants argued that they needed to actively elevate concerns about their life and health above what others think or say. Following the biblical teaching, the children of Israel faced the famine problem and ended up in Egypt, where they got food. They were there for a long period but the next problem was slavery. Their God, through Moses' courageous leadership, liberated them. They were in the wilderness for forty years but they had to persist until they reached the Promised Land. Can HIV and AIDS be compared to the tough days the Israelites went through? There was stigma before they crossed the red sea. There was stigma when the water shortage hit them, until Moses got water from the rock. The next catastrophe was the snakes that attacked them until Moses got a solution.

## **7.5 Discussion**

This study was conducted to assess the responses and coping mechanisms of HIV stigmatized youth in Kampala. The findings revealed a significant shortcoming to adhere to the very important medication of ART regimens while simultaneously maintaining secrecy of the sero-status that Youth Living with HIV and AIDS grappled with. This seems to be uniquely so in Makindye and Nakawa communities where they live and interact closely with people with divergent views on

HIV and AIDS, and youth living with it. YLWHA always had to weigh the risk of taking ARVs medication in their respective communities and the benefit of living with others. Since ART showed more immediate outcomes of improved health compared to working, they were always quick to disregard the latter. The key risks associated with taking ART at the workplace as reported by participants were unintentional disclosure and subsequent discrimination (C. A. Brown et al., 2021; Kalichman & Simbayi, 2003). From the findings HIV and AIDS was theorized as a concealable stigmatized identity (C. Logie & Gadalla, 2009). Our findings show that within communities and the school context YLWHA are highly noticeable.

Both internalized and externalized overt and covert forms of HIV-related stigma are reported in this study. Our study reinforces findings from several other studies on disclosure and medication adherence among YLWHA, reporting HIV-related stigma as a key hindrance in communities (Arinaitwe et al., 2021).

This study of stigma and HIV and AIDS treatment-seeking behavior has a direct relationship with the social construction and postmodernist views of knowledge. This implies that communications research involves understanding how human beings use language individually and in social situations to give meaning to particular views of the world. People such as social workers use language in this way to influence clients, which means that the processes through which they do so give power over clients (J. M. Turan et al., 2019). This model has connections with cognitive behavioral theory, because of their psychological base, and experimental, research-based epistemology, social psychological approaches to social work; they also have close links with cognitive approaches to social work. However, the focus on interpersonal, intergroup and therefore on language and communication have led towards a more social learning and cognitive approach and away from traditional behavioral views (Burnham et al., 2021; Galle, 2020).

Yet according to the Self-Stigma Narrative Theoretical model, self-stigma is a common phenomenon among young people living with HIV and AIDS; however, this important research area has received little attention. Furthermore, there is a lack of clarity in the current literature on what makes individuals more or less likely to experience self-stigma. Such behaviors are associated with certain groups that carry the illness which draws on existing social constructs of the ‘other’, who are consequently blamed for becoming infected” (Deacon, 2006). In other words,

Deacon raises an important issue that people who are stigmatized experience loss of status and rejection because of the blame by society for their illness.

According to Were (1969), in the first decade of the twentieth century, there was a problem of tsetse flies and sleeping sickness along the shores of Lake Victoria. From that perspective, the Prime Minister or Katikkiro of Buganda, Sir Apollo Kaggwa, advised people to move to areas that had no tsetse flies. The advantage was the sparse population. This cannot work in the present situation when the population is very high. The HIV and AIDS scourge is not limited to a specific area and age bracket, but it is in both urban and rural places, in male and female, in babies, youth and adults. The stigma is universal. It commented that the stigma caused by HIV and AIDS also takes a universal perspective.

In the same vein, people are challenged by stigma associated with sexually transmitted diseases like gonorrhea, syphilis, STIs and others but these are curable diseases. The problem with HIV and AIDS is that the cure is not yet available. A number of Africans are still taken up with witchcraft. According to Agaba (2018) and Parinder (1970), people resort to witchcraft when they are unable to establish the cause of the disease. Based on the fact the resorting to witchcraft could have also contributed to the spread of HIV and AIDS in Uganda. This happens when a person suffers for a long period without getting cured; the relatives take the patient to witch doctors.

The witch doctors create stories around and push the causes to immediate relatives and neighbors or people at workplaces. “Child marriages refer to people under the age of 18 getting married”. The two of these persons are school dropouts and they are mainly girls. At times, they drop out of schools due to low incomes of their parents or they are orphans without serious financial support. It is a point of big concern and that is why the First Ladies on the African continent came up with their organization of African First Ladies against HIV and AIDS (OAFLA) together with the African Union. Their vision and target is to end childhood AIDS in Africa by the year 2030 and keep the mothers healthy.

The first lady of Uganda adds, “It is important that all stakeholders play their roles in ensuring the end to new childhood infections, so that children start free and stay free through adolescence, youth and remain AIDS-free; no baby should be born HIV-positive, and babies need their mothers, therefore we have to keep their mothers alive and healthy”. The stakeholders in this aspect include



the following categories of persons: local leaders, religious leaders, cultural leaders, and educators at different levels, parents/guardians, and opinion leaders, among others. The focus of these persons should be on all preventive measures, so that people who are HIV and AIDS-negative are given all the information that shall enable them to remain negative. Those with HIV and AIDS should not spread it. They should practice positive living.

It is a good move and proposal. The limiting factors fall in Africans' views that sexual education is sacred and should not be openly or publicly discussed. With that tradition, parents feel ashamed to educate their children; likewise, children dread having to ask the elders. At the same time, children depend on peer education, plus getting information via social media. The effect of current technology is equally great. Children get sex education through platforms like WhatsApp, Facebook, Twitter, Instagram, social media and others.

The gaps in communication that the youths face can cause stigma. It confirms the view which (Logie et al., 2018; Mak et al., 2007) propagated, of self-stigma. It held that self-stigma is a very common phenomenon among youths living with HIV and AIDS. The messages they get on Facebook, WhatsApp, and Instagram sometimes have no detailed explanations. The youths who cannot afford modern technology only get information through peer education. It is information from least informed sources that could be said that they depend on ignorance (Ousley, 2018). It said that the youth depend on half-baked information. The youth are taken up with the common notion that a boy must have a girlfriend and equally a girl must have a boyfriend. The move forces them into unprotected sex and, consequently, unwanted pregnancies. Furthermore, the spread of HIV and AIDS cannot be controlled.

The desire to have children is still great in the African context (Mbiti, 1969). Girlfriends feel that in order to strengthen relationships with their boyfriends, they must have children with them. (Mbiti, 1969) says that a person without children is counted to be among the living-dead. The scare of being counted among the living-dead forces Africans to have children at all costs. The childbearing drive is so great that even in the Roman Catholic Church there are boys that drop out from seminaries because they want to get married and have children. The parents and immediate relatives sometimes play a big role in influencing boys in seminaries to drop out. The threatening

message they give is that it is not good to remain without children. Parents and relatives are more interested in seeing their daughters with babies irrespective of their health status.

The key issue is that people must leave behind their “heir”. In Luganda, “Walina okubeerawo omusika” literally meaning, “There must be an heir”. On the male side, the heir is expected to be a boy and a man is not content if all his children are girls. He has to get a boy-child in order to get contented among men. On the female side of females, they need to have both boys and girls. A woman who has a baby boy will remain with the urge to have a baby girl. The dilemma becomes great when the youth between the ages of 18 and 24, who are sero-status of HIV and AIDS, struggle to have children. They know that death may occur at any moment but they must get children first. The risk of spreading HIV and AIDS remains prevalent.

Poverty is another crucial factor in Uganda. The two participants out of five are living below the poverty line and they are surviving on a hand-to-mouth type of income. This means that what they receive is what they eat. The local expression is “we look for our daily bread”. Therefore, the concerned persons shall easily accept anything that brings in an extra coin. It explains why in places like Kampala a person can easily accept something like twenty thousand shillings. The task given him is to be a “husband” and take somebody’s wife to an antenatal clinic. The expecting mother does not want her husband to know the HIV and AIDS status. It is without doubt the expecting mother is HIV-positive and simply looks for a way of hiding the truth from her husband. It stays that way because the expecting mother’s target is to get a baby. She does not count the cost and effect. The person who pretends to be a husband remains happy because he has received the “daily bread”. He does not think about the harm extended to other people.

Social services in Uganda are privatized almost to a 50% extent. The social services include education, transport, health, among others (Brown et al., 2016; Erena et al., 2019; Winchester & Macgrath, 2017). There are government health units and private ones; government schools and private ones. The money motive is high in private enterprises. Where there is making money, the spirit of professionalism is likely to suffer. The dealers will do anything for the sake of getting money. The greed to get money is likely to force some health workers to be bribed and present false results. This could be showing a person who is HIV-positive as being negative. The common

intention is to hide the truth from the spouse. It could be a sugar daddy or sugar mummy that does not want others to know their status as far as HIV and AIDS is concerned.

There is the possibility of forging medical documents. It is sometimes called “visiting Nasser Road” in Kampala. The persons who do not have the ability of knowing authentic medical terms can easily be deceived for either having the disease or not. In that way, those who use money to have their way can manipulate unsuspecting people. Some innocent people are exploited due to ignorance and poverty.

Mass media: local herbalists, diviners and leaders of independent quack churches to create imaginary confidence among readers, viewers and listeners and so on can equally use TVs, FM radios, newspapers. A sick person can depend on such false confidence and fail to go to established health facilities like Mulago, Mengo or Nsambya hospitals.

A case is cited of patients of cancer, Hepatitis B, HIV and AIDS being urged to go and receive miracles at prayer meetings. These people are psychologically manipulated and the onlookers can easily fall into the same trap. The people who own herbal centers are also common in FM radios, especially during evening hours and promise to plant heaven on earth. The HIV and AIDS patients, especially the youth, go to them for assistance.

There are organizations that have come up to support HIV and AIDS sero-status; one of them is TASO (The Aids Support Organization). It has served in Uganda for over thirty years. The challenging thing is that their services have not reached many people in Uganda. Then there are the ARVs provided by the Ministry of Health in Uganda, but the concern remains how many people go for them; and even those who go for them, there are those who do not adhere to the instructions given by medical personnel. The best option would be to sensitize people, starting with the youth, about the HIV and AIDS scourge and its consequences.

However, critically looking at the study findings in relation to the theoretical models that guided the study, the social psychological and communication theoretical model that was developed by Woodgate et al., (2017) emphasizes the effect of relations within and between groups on creating and maintaining social identities. These include ideas about how people behave in relation to, and therefore, influence others and the effects of social factors such as stigma, stereotyping and

ideology on behavior in groups. The model puts into consideration social psychology and its effects of communication and therefore language and speech upon social interaction in order to understand stigma and its power dynamics (Arinaitwe et al., 2021; Kalichman et al., 2020; Logie et al., 2018).

Based on the results of this study, it is clear that abolition of a restrictive policy such as the requirement for an HIV test prior to being employed, for example to the army, does not guarantee an immediate understanding of that policy. In light of this finding, strategic efforts need to be made by social workers and other professionals working with these youths (Logie & Gadalla, 2009; Mahajan, 2008; Twikirize & Spitzer, 2019). This strategy will be geared toward sensitizing this category of age group to changes in employment laws and health policies, as well as the implications of these changes.

The analysis of stigma and perceived barriers to HIV testing also revealed the need to assess and address the level of awareness and understanding of issues concerning the youth and healthcare policies and resources. Findings from this study can be used to sensitize social workers and others engaged in policy making to the inaccuracies and incompleteness of epidemiological data about this population (Brown et al., 2010; Erena et al., 2019; Kalichman et al., 2020; Logie et al., 2018).

It was evident that some of the study participants indicated that they were HIV-positive. At this time, Uganda HIV and AIDS case surveillance does not mandate recording of place of birth and prevalence data for youth as per (Abebe et al., 2019; Bongomin et al., 2019). Hence, HIV and AIDS prevalence number of youths may be erroneously subsumed under HIV and AIDS prevalence rates (Seffren et al., 2018; Twikirize & Spitzer, 2019). This wrongful categorization may artificially increase the HIV and AIDS diagnosis rate of the youth and lead to misguided targeting of preventive and care resources while obscuring specific needs of the youth.

The current data indicate that the two that can lead to misguided targeting of HIV resources may also disempower the youth community further. This can be through failing to provide them with the information needed to take appropriate actions, take charge over their lives, or connect with other groups who share similar HIV-related features. As Collins (2005) cited Amadi (2012), to empowerment is a collaborative process that includes encouraging communities to develop a broader agenda of social justice with other groups with similar concerns.

Becoming culturally competent is a developmental process in which one learns to acknowledge, appreciate, and adapt to diversity; to evaluate one's own knowledge, beliefs, and attitudes about other people's cultures; and to integrate the patient's beliefs and customs into the healthcare delivery process (Teixeira da Silva, 2020; Hogg et al., 2017). The present study supports efforts of the social work profession to build cultural competency among providers who interface with the youth in the healthcare system. In using this strength-based, culturally sensitive approach and by use of the empowerment model, it should be noted that power arises from a group.

In addition, it is observed that an outside-based intervention may undermine the development of the internal strengths of the group. Using the perspectives put forward by Arai (1997), by which empowerment is seen as a transformation process, with the goal of changing the thresholds of powerlessness and increasing people's control over their lives, social workers might work, as this investigator did, through community-based organizations. In this way, social workers should make conscientious efforts to decrease professional dominance and to enhance youths' ability to make choices and realize self-determination (Choko et al., 2018).

## **CHAPTER EIGHT: REFLECTION, FINAL DISCUSSION, CONCLUSION AND RECOMMENDATION**

### **8.0 Major Findings, Implications and recommendations**

From objective where youths' perception and experience of HIV and AIDS stigma, the findings, revealed that HIV and AIDS positive youth perceived and experienced different forms of stigma. This includes; social stigma, self – stigma, felt stigma and internal stigma but not limited to those who are peers of most - at – risk young men and women, those that live without parental care or protection, or live with older relatives or guardians or in dysfunctional families. This group includes the youth who are unemployed, or are isolated that may impair their judgment, or live in broken communities and situations where social and sexual norms regulating behavior are non – existent or are loose. The youth who have limited access to health and social services due to lack of emotional and psychosocial supportsuffersevere psychological and social consequences.

Participants experienced internalized stigma that is applicable to the experiences of YLWH in Nakawa and Makindye Divisions of Kampala City. Although limited in number, participants reported personal experiences of unfair treatment by others (enacted stigma) or external stigma and discrimination. Felt stigma is a danger to an individual as enacted stigma since it leads to restriction of social support and withdrawal. Which were similar to experiences reported in other investigations (Friedland, 2020; Kooij et al., 2021b).

Notably, participants had strong expectations about the forms of normative stigma i.e. subjective awareness of stigma which it is expected will motivate individuals to take action to avoid enacted stigma, (felt normative stigma), which led them to limit disclosure of their infection. However, their personal views about HIV stigma was nuanced, often reflecting general disapproval of stigmatizing beliefs but leaving open the possibility that discrimination was sometimes appropriate (internalized stigma). In addition, the interview responses highlighted how hearing about enactments of stigma represents an important source of perceived norms of stigma.

Study findings revealed that treatment seeking was not a common practice upon confirming the positive status of HIV and AIDS. Fear of rejection, lack of disclosure, denial and being asymptomatic, belief in witchcraft and spiritual beliefs were barriers identified at individual level among youth living with HIV. This remains a matter of facts mentioned in the previous discussions. All these are integrated in a Stigma Treatment Seeking Behavior (STSB) analytical

framework to illustrate the contribution to the existing body of knowledge as gleaned by the researcher. The chapter ends with the study recommendations, limitations and suggested areas for further research.

Implications of findings in the study, it was found that there was full awareness of the existence of HIV and AIDS among the youth. The youth were aware of its dangers. They perceive it as a curse and others as a sure way to death. The youth are experiencing stigma and they see life as being meaningless. They are only waiting for their last days and dying. The youth are going through a stigmatized situation.

### **Recommendation**

Community outreach programs and community-based projects offer opportunities for young people to receive advice and information in more ways that are informal. In addition, reach youth outside the school system through community-based strategies. Community members have a huge potential to support and reinforce HIV prevention interventions, talking to youth in a more informal and comprehensible manner. A number of international and local NGOs currently involved with community mobilization activities can be successfully applied to improving youths' HIV and AIDS/sexual health knowledge and skills (Jiang, 2020; Kooij et al., 2021b; Ponticiello et al., 2020).

The public should stop making bad comments towards HIV and AIDS sero-status in particular and all patients in general. HIV and AIDS stigma education and public awareness can take place in many different environments; from classes at school to families and friends sharing knowledge at home. It is important that this education is provided in a variety of settings to ensure that the most vulnerable and marginalized groups in society are reached. Even accurate information about HIV and AIDS stigma is reinforced from different sources (Brown et al., 2021).

The commonest place for people to learn about HIV and AIDS stigma and discrimination is at school. Due to their capacity and universality, schools are a crucial setting for educating young people about AIDS. As young people are at a high risk of infection, it is vital that they get educated about HIV transmission before they are exposed to situations that put them at risk of HIV infection. That is, before they are sexually active. Schools play a major role in shaping the attitudes, opinions and behavior of young people, so they are ideal environments for teaching the social as well as the biological aspects of HIV and AIDS (Gachanja et al., 2018; Kimera et al., 2019a).

## **8.1 Reflection on HIV stigma and treatment seeking behavior**

From the findings, it was established that HIV related stigma negatively affects young people's treatment seeking behavior. All the youth who participated in the study did not seek treatment immediately even after establishing their HIV sero status. The reasons they mentioned for not seeking treatment included; fear, rejection, isolation and discrimination. In addition, treatment-seeking-behavior of the youth was explored as reasons for delay in initiation of ART, reasons for preferring the center, accompanying persons, travel distance, mode of travel, and expenditure per visit. Family support to the participants at times of follow-up visit and collection of drugs was studied. After advice to start ART, there was a delay in starting treatment among one-fifth of the participants. The study findings revealed the reasons for this delay included; depression, fear of rejection, fear of disclosure to family, and fear of side effects.

It was revealed that treatment – seeking was not common practice upon confirming the positive status of HIV and AIDS. Participants reported that discrimination, non – disclosure, denial and being sero negative, belief in witchcraft and spiritual beliefs were barriers identified at individual level. However, following a delay in seeking for treatment, a few factors that brought a positive turnaround include providers' level, support and good patient-staff relationship, which facilitated linkage, while negative attitudes and abusive language were reported barriers to successful linkage to seeking treatment. Clear referral procedures and well-organized clinical procedures were system-level facilitators, whereas poorly organized clinical procedures and visit schedules, overcrowding, long waiting times and lack of resources were reported barriers.

The study exhorted various reasons for patients preferring this ART center—around the two-stated comfort, small number of participants added confidentiality and privacy, and, for only two participants mentioned, this was the nearest health facility. All of them collected drugs once a month; ten of the participants found the monthly visits convenient.

All these factors explain the nature of HIV treatment-seeking behavior among the youth. In addition, the findings revealed the following treatment-seeking behavior: two of the youth participants were willing to go for voluntary testing of HIV and AIDS. Some of the participants reported that they go for testing after being compelled, by conditions like severe sickness, going for antenatal services, waiting or preparing for marriage. They did not want to disclose their HIV and AIDS status to other persons. They tried all possible ways to hide their sero status. There are



those who do not adhere to the instructions given by health workers. Those who adhere to medical instructions have minimal problems. Not all youths show interest in counseling services that are offered at different health units.

### **Implication**

The implication of these findings is that establishing one's HIV sero status is not enough and does not necessarily serve as a motivator to seek treatment by the youth. Instead, the negative labeling of one who is HIV positive appears to have greater influence in serving as a demotivator to seek for treatment. This is surprising given that even after more than 30 years of HIV and AIDS education, stigmatization against those who are so positive is still strong.

It is important to reflect on the factors that served as catalysts for seeking treatment even in the presence of stigma. This is important given the fact that at some point the youth eventually sought treatment. From the analysis, we see that the positive influence of peers living with HIV and AIDS served as an important turning point. The implication of this is that peers/peer groups are and should be important structures to forget influencing behavior change. Indeed, literature supports this view and several studies highlight targeting significant others, youth peers.

Late antiretroviral treatment initiation for HIV treatment worsens health outcomes and this contributes to the ongoing transmission. This kind of delay in getting treatment on time, for some individuals can compromise the fight against the HIV and AIDS epidemic. For the youth living with HIV, late treatment initiation is associated with higher propensity for treatment related adverse events and lower chances of achieving viral suppression. In addition, late treatment is an implication that increased AIDS and non-AIDS related morbidity and mortality. Thus, at this youth population level, late treatment initiation implies potential onward viral transmission from unsuppressed HIV viral load among those living with HIV. While on the other hand, seeking treatment early and immediately is important for reducing and curbing the risks of mortality and improving quality of life among the youth living with HIV.

## **Recommendation**

The youths still need sensitization about HIV and AIDS, the harm it causes to themselves and their relatives. They need to be aware that as we stand, there is no known cure for HIV and AIDS. Use all possible avenues to educate the youth. Parents/guardians, teachers, religious leaders, politicians and all opinion leaders should participate in this crusade. Educating people at work is an important way of providing people with vital prevention information, and can reach people who have previously missed HIV and AIDS education programs. Furthermore, it is estimated that nine out of ten people living with HIV are working. Providing education in the workplace is important for protecting those at work who are living with HIV, and for helping them to live healthily and stay in work. Some occupations carry an increased risk of HIV infection, making HIV and AIDS education in the workplace even more important for preventing the spread of the virus.

The varieties of methods and materials that are used to educate people about HIV and AIDS, especially in communities, include radio and television, social media, booklets, billboards, street theater, comic strips and many more. The form in which HIV and AIDS education is delivered depends on the characteristics of those who are being educated. In order to reach the target group, it needs consideration which environment will be most receptive in and what media is most relevant to them.

HIV testing needs to be regular and the youths, if not every person, need to be encouraged to go for such tests. People should be encouraged to go for regular testing. The education program concentrates on the prevention of HIV and AIDS transmission in urban and rural communities through education, counseling and testing. This evidence is based on interventions and community planning. The program offers free HIV and AIDS services through Anonymous and Confidential testing using a twenty (20) minute Or Quick test that provides clients with their results before they leave the clinics. The program provides HIV counseling testing and referral services; free anonymous and confidential tests, culturally sensitive HIV pre- and post-test counseling to at-risk individuals who wish to know their HIV antibody status. Provide referral services for all clients who test positive.

The findings of this study also support Goffman's theory of educating society on stigmatization and its effects. This study recommends that such education be provided at the different levels of society, where stigma and discrimination happen among family members, individuals,

communities, institutions, government policies and practices, media, and friends. From this study, it was found that participants perceived the effects of stigma among the youth on two levels; the current and the future burdens, but beneath this is a third level that helps them to cope with their situation.

## **8.2 Role of HIV stigma in influencing treatment**

In the third objective, the study examined how stigma has affected the youth living with HIV by getting treatment. The study findings revealed a depressing picture discrimination, rejection, and fear. The findings of this study have demonstrated that stigma in Kampala, an urban setting in Uganda, is a social construct that was influenced by a number of socio-cultural factors. These include religion, beliefs, knowledge and social structures such as gender. The interplay of these factors has contributed to the people's negative reaction towards receiving HIV and AIDS diagnosis, treatment and care. It has also created a negative attitude in the public towards HIV and AIDS, as indicated by the gruesome experiences of the youth living with HIV and AIDS at different levels.

Youth's reactions to such threats to discrimination fear and rejection to social acceptance and belonging as they occur in the context of diverse issues such rejection, discrimination are betrayal and stigmatization. According to the findings, youth's immediate reactions were quite similar across various forms of rejection in terms of negative affect and lowered esteem. However, following these immediate responses, the youth's reactions are influenced by construals of the rejection experience that predict different motives for anti-social, socially avoidant behavioral responses and pro social.

It was reported that HIV and AIDS is as much about social phenomena as they are about medical and biological concerns. HIV and AIDS is associated with discrimination and repression, and includes individuals living with HIV who have been rejected by their respective families and communities as a whole. The friends, loved ones, families and some members of the communities as a whole evict some YLWHA from their homes. While conducting interviews with participants, they reported that they were turned away from health care services, by not being given specific schedules for their visitation, breach of confidentiality about their HIV status; and health service providers who are in short supply often hold negative attitudes, and at times are seen as incompetent.

It evidenced that both youth, female and male between 18 – 24 years are more likely to be negatively treated and discriminated against by family members. I learned that some YLWHA find their families, health service providers and neighbors to be supportive. It is also explored in this study that Nakawa and Makindye people still believe that sharing utensils, casual contact or being in the same room with an individual living with HIV could put you at risk for HIV infection. Although there is not much reported on HIV transmission in their place of work the supposed risk of transmission has been used by several employers to terminate or deny them jobs or employment. I also found out that if YLWHA are open about their HIV status at the workplace or at school they experience stigmatization and discrimination by other members within the same environment.

The results of this study indicate that there is a need to work around the issues of HIV and AIDS stigma in Kampala and probably other communities of Uganda. There seems to be a gap between the relatively small body of research on what stigma is, and what to do about stigma in society, which this study has brought to the forefront. Many people perceive that the communities have negative attitudes towards people, especially the youth who are living with HIV and AIDS.

Among other challenges are poverty, unemployment and other life opportunities. There is a possibility that some of the people who stigmatize others do so without the knowledge that their actions are stigmatizing, because of the way stigma is defined in the Ugandan urban setting (Ajayi et al., 2019; Eisinger et al., 2019). According to the findings, it is indicated that HIV and AIDS stigma is not static but changes with disease progression. However, the findings indicated, some of the challenges the youth living with HIV and AIDS experience as being scary, other people living with the disease managed to come out into the open to give a human face to the epidemic in the fight against stigma.

### **Implication**

From the analysis the effects of rejection and discrimination on hurt feelings have been replicated with many ways of inducing rejection including, leading participants to think that they are considered last in any communal and school activities. At times, in health centers it was revealed that some health providers were not providing clear feedback about medication indicating that another participant was not interested in what they had to say in clinics, giving clear feedback to participants is very important. That indicates that they are not discriminated against and rejected. Participants feel accepted and valued and they feel very strong with self-reported hurt feelings.

The youth tend to involve experiences in which they felt devalued, unimportant or rejected. Importantly, youth sometimes feel the pain that is associated with significant rejections such as betrayal as high as that associated with pain experienced by chronic disease like cancer.

Other emotions sometimes arise, when the youth are rejected and discriminated against, particularly anger and sadness, but these emotions are probably not direct effects of rejection per se. Unlike hurt feelings, which appear to arise particularly from rejection or relational devaluation, these other emotions may be exerted by other features of the rejection and discrimination.

### **Recommendations**

Youth should be helped to understand that being HIV + is not the end of their lives. Both the youth and community should be helped to reduce fear of each other through the use of practical activities. Encourage the youth to go for voluntary testing. Encourage the youth to seek treatment and care services. A similar study should be done with a representative sample covering many districts in Uganda to strengthen the youth. Social workers involved in direct service, research, agency leadership and advocacy aspects, should utilize the findings to enhance cultural appropriateness and effectiveness of their work

It is very important to understand the target points for interventions to be able to help these vulnerable young men and women. Interventions can target any of the stages identified in this category of populations by: 1. increasing support to these youth and providing them with other alternatives to help them cope with their situation. 2. Providing interventions and policies that can help reduce the current economic and social burden they face because of their HIV status and 3. Providing interventions and policies that will help them cope better with their future. Much as some people are challenged by stigma, they are entitled to good counseling.

Involving parents and families is critical, as parents are influential and important sources of information for youth. They are best in providing individual support and education, starting from early in their children's lives (Begun et al., 2020; Cao et al., 2020; Ferrie et al., 2020; Friedland, 2020). Although most are in rural and urban communities, adults want young people to know about abstinence and how to prevent HIV and sexually transmitted infections; parents often lack skills and have difficulty communicating about sexuality (Anderson-Carpenter, 2021; Stockton, 2018; Safreed-Harmon, 2020).

Yet communicating about sexuality is important -discussions between parents and their children help young people to establish individual values and to make healthy choices. Positive attitudes toward school and reduction in risk behaviors, such as substance abuse, are also benefits of constructive relationships with parents. Indeed, strong family relationships can help children develop confidence, withstand peer pressure, and behave responsibly when making decisions about smoking, drug use, violence, and sexual intercourse. Effective parent-child communication is the key to well-built and healthy families. In the HIV and AIDS education program, parents should learn ways to converse more competently with their children. How and what they tell about body appearance, peer pressure, puberty, human reproduction, sexuality, love, and intimacy can have a considerable impact on the health and well-being of their children (Bassey et al., 2021; Rubtsova et al., 2021; Shiau, 2020; Kirby, et al., 2021).

Efforts should be made to promote programs for treatment. HIV and AIDS patients, like any other patients, have to seek treatment. The International Labor Organization (ILO) works throughout the world on HIV and AIDS policies and programs in the workplace (Gombe et al., 2020; Skovdal et al., 2021). The program aims to protect against discrimination in labor laws, promote prevention initiatives within the workplace, and support those living with HIV. It ensures access to social protection, treatment and care. However, workplace HIV and AIDS education is not universal and as a result, people are still unaware of the dangers of HIV. Those living with the virus are still subject to HIV-related stigma and discrimination at work (A. & R., n.d.; Demirtaş-Madran, 2020; Feyissa, 2018a).

An education program for HIV and AIDS stigma and discrimination is delivered, depending on the principle aims of the program. Sometimes education on HIV and AIDS is about giving people information that they will remember on a long-term basis, about how to protect themselves; the difference between HIV and AIDS; helping to reduce stigma and discrimination. Other education strategies are intended to have more immediate effects (Feyissa, 2018b). They may target people when they are most likely to take part in risky behavior -in nightclubs or holiday resorts, for example. A variety of methods and materials are used to educate people about HIV and AIDS especially in both urban and rural communities. These include social media, radio and television, booklets, billboards, street theater, comic strips and many more economic and psychosocial challenges.

#### **8.4 Responses and Coping mechanisms**

In the fourth objective, the study sought to find out how the youth responded and cope with the HIV stigma in Kampala. This was after realizing that for the sero-status of HIV and AIDS, life has to continue. They have to find a way of getting used to the situation. Those who coped with stigma adhered to the medical instruction, responded and coped in the following ways: accepting that they are already sero-status of HIV and AIDS; and they have to live with it; following the medical instructions given at health units. The services offered in Kampala at different units were found to be reasonable; people work normally and they do not avoid duties. They behave as if there is nothing wrong with them, and offer counseling services to other persons who need the very services.

Throughout the interviews, stigmatization was one issue that all the participants reacted to as a big problem when it comes to HIV and AIDS. With reference to the results I got from the participants, stigma and discrimination are obstacles blocking the provision and uptake of prevention, treatment, care and support. Goffman's theory of stigma has a significant relevance on the empirical findings of this study. In a nutshell, Goffman explains the importance of educating 'the normal' (the individuals who stigmatize) on the conditions of the stigmatized, how they feel when stigmatized and examples of those who are stigmatized but have been able to make a difference in the society, as the best way of reducing stigma to certain conditions that prevail in the society.

Some participants reported a positive perception that they have accepted their HIV status. For this case, education was found to be the enabler that has nurtured the positive process of accepting their status and has encouraged them to disclose their status. Generally, it was found that youth are aware of HIV and AIDS but lack accurate information or knowledge of the disease. Several negative perceptions and experiences were reported in the Focus Group Discussions. These show that some parents and community members stigmatize YLWHA and discriminate against them. Worse still, some YLWHA were psychologically affected after they disclosed their HIV status.

#### **Implication**

One of the participants mentioned, "Life is so easy on ARVs, once someone accepts it" this implies that acceptance, denial are linked to HIV care in Uganda. From study, findings suggest that HIV status acceptance is very crucial for a person's engagement with HIV care and access to social support, quality counseling, knowledge, attitudes, and practices regarding health care. Another

implication about disbelief on receiving a positive diagnosis can hinder access to care. Disclosure of HIV status among the youth living with HIV links to seeking treatment and care services. There are perceived benefits of accessing treatment early, even when there are no AIDS symptoms.

Factors of effective group psychotherapy and individual psychotherapy - based interventions that seem to help individuals living with HIV and AIDS. Firstly, the provision of HIV information about the nature and function of stigma is important in order to provide an explanation of how these processes work. This enables youth with HIV to consider and understand how the process of stigma works and allows them to place their own experiences within an articulated and explicable analytical framework (Campbell, 2021).

From the findings of this study it is important that there is a discussion about how the experience of stigma emerges in the lives of youth living with HIV. As discussed before, stigma emerges in many various forms and may not immediately be experienced as the effect of stigma. The Intervention needs to contain ways of identifying personal emotional and cognitive responses to HIV stigma and ways that the effects can be recognized and countered (Campbell, 2021). The cognitive-behavioral framework that was used in this study was effective at managing negative thoughts and emotions that are useful. A psychological approach to identifying negative thoughts, feelings and beliefs about the self that underpin behaviors that are consonant with the underlying beliefs is a powerful tool.

From study findings, participants reported that if one's beliefs about oneself are negative then one's thoughts and feelings are also negative. Behaviors, especially in domains associated with the negative beliefs (healthcare, HIV status and medication) are likely to be affected negatively thus reflect the underlying stigmatized beliefs. The CBT framework always begins with the identification of negative beliefs about oneself and then continues to an exploration of how personal behaviors reflect these beliefs. This can be a very powerful process for youth living with HIV who may have never encountered a systematic exploration of how they may feel about themselves and examine how their previously unspoken feelings are reflected in important self-care behaviors particularly with regard to managing their HIV disease (Campbell, 2021).



## **Recommendation**

The findings in this study tackle some important issues. First, there is need to intensify educating the public about HIV and AIDs and the importance of making the general population aware and convinced about the mode of transmission, which is not through social contacts such as a handshake, a hug, or any form of social gathering; and that transmission is also not contagious, as it seems to be. The education can start from the very early stages in primary schools, to high schools and universities, about how people living with HIV are living healthy lives. This may even live up to their biological life spans. The public should also be educated about the success stories of people living with HIV. Secondly, reinforce human rights laws governing the labor market so that the youth living with HIV are secure in their work as far as they are able to do their work effectively. There should be no discrimination against sero-status based on their HIV status. This will even reduce their current psychological problem of always thinking about the fear of the future workplace stigmatizing against youth living with HIV.

Thirdly, there is a need to strengthen the social system so that families and the government, through good social policies, especially concerning youth living with HIV, can support youth who are not yet in the labor market and infected with HIV. These three points or measures need to be put in place by governments, stakeholders and international bodies, like the UNAIDS and the joint UN team on HIV and AIDS. Otherwise, it will be very problematic to achieve zero new HIV infections, zero stigmatizations, and zero HIV related deaths, which are very important public health goals.

It was evident from the study that barriers to using HIV care services included fear of rejection and HIV disclosure, young men and women's lack of support from their families; demanding work schedules, and high transport costs. This encounter of experienced barriers to seek HIV treatment and care among the youth living with HIV and AIDS in Uganda is a problem. In the face of the magnitude of the HIV epidemic, and the central role played by young people in sub-Saharan Africa, there is an apparent lack of stigma-focused interventions in Uganda. This calls for more research and scrupulous use of available resources to inform the design and delivery of well-tailored interventions to meet the unique needs of this population group in communities (Havlir et al., 2019a, 2019b; Makhema et al., 2019a). Future research projects employing a systematic approach, once a contextual framework for the intervention is established, are urgently needed to help reverse the course of the AIDS pandemic (O'Brien, 2020). Understanding the role stigma

plays as a barrier, and testing intervention geared toward reducing stigma would be essential components in such projects.

Understanding stigma as a problem of fear and blame, rather than a problem of ignorance, helps us to appreciate the stigmatization process without resorting to individual isolation. Often people blame and judge those who are living with the disease as if they deserve it, because this scourge of HIV and AIDS is associated with unacceptable sexual behavior. The perception is that HIV and AIDS is a “bad disease” linked to high risk behavior such as promiscuity, drug use, so people distance themselves from it.

Therefore, the exposure of knowing someone living with HIV and AIDS has a deeper impact on individual and community perception of this disease. HIV and AIDS is strongly associated with stigmatization, discrimination, blame and judgment. The overall conclusion drawn from this research finding is that there is a high level of stigma associated with HIV and AIDS in communities, most especially where the research study took place. At a personal level, people expressed negative attitudes towards youth who are living with HIV and AIDS and always have retained misinformation about the transmission of HIV. This study has demonstrated that some people still believe that HIV is transmitted by casual contact, which is false.

If we are to address the challenge of HIV stigma and prevention of HIV and AIDS among the youth, designed programs targeting psychosocial antecedents of risk behavior will play a significant role (Akilimali et al., 2017; Arnesen et al., 2017; Ebrahimi et al., 2020). More and new innovative intervention approaches/techniques will continue to evolve, encompassing principles of the youth development and being responsive to changes in the social and biological factors that have substantial influence on the youth’s health behaviors (Anderson et al., 2020; Audet, 2016; Arnold, 2018; Sharma et al., 2017). However, optimizing HIV stigma, AIDS prevention efforts in future will require prioritizing the development and evaluation of innovative, empirically driven, rigorously planned research tailored to the cultural, theory-based, and socio- demographic characteristics of the target population of the youth.

After nearly a decade of increasing the provision of ARVs and ART in Uganda, YLHIV still experiences verbal and social stigma, discrimination, blame and rejection by spouses, and/or mistreatment by health care workers, albeit to a smaller extent compared to the pre-ART/ARVs era. These unhealthy experiences have a negative impact on treatment adherence. Efforts to reduce

stigma and discrimination that started earlier in the pre-ART period with the purpose of encouraging HIV testing are still relevant now and should be given more impetus so as to maximize positive treatment outcomes. Such efforts should contribute to helping ART clients apply adaptive coping strategies, such as those identified in this study that include accepting the illness, seeking information and/or exchanging views about the illness through support groups, and preemptive disclosure (Elul et al., 2017; Nyblade, 2021).

Stigma among the youth remains a barrier to all the essential components that make up a good prevention program, and much detailed research on stigma reduction is needed to improve the components of a good prevention program. Overall, chapter four, five, six and seven presented, analyzed and interpreted authentic data collected as indicated respectively. The data presented, analyzed and interpreted was strictly based on the study objectives in an attempt to answer the research questions.

The findings indicated that stigma among youth remains an enormous barrier to effective fight against HIV and AIDS treatment-seeking behavior. YLWHA in Nakawa and Makindye Division perceived and experienced stigma related to HIV differently. Fear of discrimination and disregard often prevents the youth from seeking treatment for HIV and AIDS or from disclosing their HIV status to their close friends or parents. Some are coping with the disease and open about their HIV status. From this perspective, education and information from different stakeholders, support groups were found as an existential behavior and enabler that needs to be part of our day-to-day practice.

## **8.5 Theoretical Reflections**

Youth's perception of HIV somehow affects the way HIV-infected people perceive themselves. The youth in this research feared and projected stigma and discrimination based on their own beliefs of what people might think of them and how people might act towards them. Some youth stated that their fear of HIV-related stigma from the community was based on lack of social support they received from the community and health centers. Youth in this study had experiences of self-pity, they felt isolated, neglected themselves and denied the fact that they were living with the virus. Their behaviour was also confirmed by the enacted stigma scale results, as some youth indicated that their partners had left them because of their HIV-positive status. One of the participants indicated that she no longer went to the public functions to have their social

interactions; whilst most of them pointed out that they preferred to avoid social contact. The types of treatment the youth received from their families largely determined the way they related to their families thereafter. Their loss of interpersonal contact left the youth with feelings of isolation. From the findings it was revealed that internalized stigma often proceeds, rather than results from, the enacted stigma. They claim that many individuals reduce the opportunities for enacted stigma in order to protect themselves from discriminatory actions.

According to the findings Cognitive theoretical framework teaches the youth how certain thinking patterns are causing symptoms – by giving a distorted picture of what is going on in life, causing the youth living with HIV to feel anxious, depressed or angry for no good reason, or provoking themselves into ill-chosen actions.

Therefore the theoretical models on HIV stigma were considered useful; however, one of them was adopted in this study. The theoretical model included cognitive behavioral theory and its importance in this study. The Cognitive Behavioral Theory developed by Skinner et al. (2020) is applicable in gaining an insight into understanding the perceptions and how stigma is felt. Stigma in this case was viewed as a cognitive aspect of human behavior. Beck and Skinner predict that a person's cognitions influence behavior and vice - versa. Cognition is a thought or a perception, a belief, a feeling, or a point of view. One implication of this cognitive behavioral model is that if the cognition can be altered, the behavior can be altered too (Slavich, 2020) in this case of stigma it is linked to attitudes and behavior of an individual. This portrays the importance of cognitive behavioral theory in the study of stigma and HIV treatment-seeking behavior among the youth living with HIV..

The useful part of Cognitive Behavioral Theory (CBT) framework on fear, and HIV treatment seeking among the youth portrayed about the person's attitudes and behavior in relation to reproductive health and feelings that they have experienced. It brought about awareness of the effects of the disease on the individual's body, the ways to cope with it, the changes and discomforts experienced by the client, and with those problems. It explained psychological problems the youth encountered in their respective lives. The person's mindset about the disease, and feelings that s/he has experienced with the disease provided an explanation of the psychological empowerment strategies of the person.

The awareness about sexual relations, brief training of the sexual response circle, the impact of HIV on sexual relationships, strategies for improving sexual relations, attitudes about sex and the problems faced with this, experiences of sexual health. To deal with sexual problems to express issues of self-disclosure to a partner, family members and others, counseling on ways to prevent transmission to sexual partners and others needs a rethink. Understanding the way people think about responsible behavior, and the problems facing the person, the need to communicate with the family, the reasons for disconnection with the family, and an explanation about finding discrimination and stigma reduction.

The relevance of this framework is that people adopt strategies for dealing with stress; it is further influenced by the assumption that a given situation is controllable or changeable. Therefore, to deal with the stress of a given situation, adaptive strategies are developed to match the situation, including the individual's conviction and attitudes to reality. A fundamental component of the coping process is seen as an appraisal by the person facing a stressful situation, which involves an evaluation of both the demands of the situation and the personal efforts the person can exert or exerts to deal with the situation (Cao et al., 2020). The researcher, therefore, proposes a new analytical framework arising from the study findings.

### **Implications in relation to the theoretical framework**

I used Cognitive Behavioral Theory by Skinner and Beck's theoretical framework to identify and discuss factors, causes, barriers of HIV and AIDS treatment-seeking behavior among the youth living with HIV in Kampala City. The theoretical framework gave an insight into the failures and successes of previous HIV and AIDS related stigma, prevention and care intervention programs. Cognitive Behaviour Theory indicates that youth's emotions, thoughts, behaviour and body sensations, is linked to each other and that whatever people do and whatever they think, affects how they feel. Also, changes in one of these will cause changes in the others.

Secondly, the CBT approach is effective in the treatment of a wide range of mental issues and conditions, such as generalized anxiety disorders, general or post-traumatic stress, panic attacks, depression, eating and sleep dysfunctions, obsessive-compulsive disorders, and substance dependence. This was because according to most participants, cognition is a thought or a perception, a belief, a feeling, or a point of view. One implication of this cognitive behavioral

model is that if the cognition is altered, the behavior alters too. Much as this model explains that people adapt strategies for dealing with stress, it is further influenced by the assumption that a given situation is controllable or changeable. Therefore, to deal with the stress of a given situation, adaptive strategies are developed to match the situation, including the individual's conviction and attitudes to reality. A fundamental component of the coping process is seen as an appraisal by the person facing a stressful situation, which involves an evaluation of both the demands of the situation and the personal efforts the person can exert or exerts to deal with the situation (Addington et al., 2020; Buehring & Bishop, 2020).

### **8.6 Addressing stigma from social work perspectives**

From the experience I received in the field study, we can use social work approaches to fight against stigma because social work as a profession is duly committed to undertaking research and integrating the results into practice and policy recommendations consistent with the pragmatism paradigm (Safreed-Harmon, 2020; Tomaszewski et al., 2020). The findings from this study point in numerous directions for consideration by the social work profession and by the communities in Uganda. The public health community in Uganda has agreed that HIV testing is important in addressing HIV and AIDS stigma (Friedland, 2020; Van Der Kooij et al., 2021). The youth should receive positive acknowledgement that they seem to have achieved a higher rate of HIV testing than any other category of populations in hospitals.

The social work commitment to the principle of social justice is well suited for addressing the complex issues of the youth and HIV treatment seeking and health services from medical personnel in hospitals. The empowerment perspectives will enhance the application of the study's findings to work with this age group (the youth) at risk for HIV infection. This will particularly be through understanding the mezzo and macro factors, which in addition to micro factors, may influence HIV-related behaviors (Camacho et al., 2020; de los Rios et al., 2020; Rosengren et al., 2021).

In this study, HIV stigma perception was found to affect HIV testing. The study helps to clarify the extent to which stigma perception, usually seen as a micro factor, is embedded in mezzo and macro factors. This may include factors such as family and cultural values, global disparities in the HIV and AIDS epidemic, and features about youth development (Swahn et al., 2019b; Waajid et al., 2021). Such clarification can be used to amplify the impact of social work and public health planning and interventions (Herek, 2002; Logie & Gadalla, 2009). Social work professionals and

other service providers, strengthened by an enhanced understanding of socio-demographic, cultural, behavioral and attitudinal information related to HIV testing barriers for youths, are paramount (Ajayi et al., 2020b; Erena et al., 2019; Hatzold et al., 2019; Kimera, Vindevogel, De Maeyer, et al., 2019b).

Social work professionals and other service providers have a fresh opportunity to enhance advocacy, program design, and individual services for these groups. This study highlights the need for social workers working with the youth to go beyond the approaches of individual education and broad public education to identify and work with other community and structural factors in working for the improved uptake of HIV testing by this population (Feyissa, 2018a; Logie, Williams, et al., 2019; Poteat et al., 2021b).

The present study provides a window into the social work practice and cultural diversities among youths, even within groups from the same tribe. There are also different categories of youth in Uganda, including refugees, asylum seekers, and permanent residents. Variations in tribes and their respective place and status may influence HIV testing and treatment patterns (Bonnington et al., 2017b; Taylor, 2020). Failure to recognize such diversity and to adjust service provision accordingly may have contributed to findings in this research. Some youth avoid testing because of fear of anticipated consequences and fear of how providers might treat them or use the knowledge of their status (Yassin & Gebretekla, 2017).

To address the issue of stigma in AIDS prevention, news media, home videos, radio jingles, etc., should all be involved to present de-stigmatization programs in schools, hospitals, churches, and religious centers (Alhasawi et al., 2019; Lauby, 2018; Newcomb, 2017; Skovdal, 2019). The introduction of AIDS education integrated into school curriculum from the primary to university levels. Another way to address stigma can be the direct empowerment of stigmatized people, and involving them in the design and implementation of prevention programs, as recommended by Kutner et al. (2021); Newcomb (2017).

The openness of community leaders and organizations to participate in this study suggests that the youth, despite many disempowering features of their lives as youth in the country, are ready and willing to move forward collectively for their own empowerment (Nyblade, 2009; Ogden & Hills, 2008; Scambler, 1998). In the current study, HIV stigma is seen as one of the barriers to HIV treatment and seeking for health services. This strongly suggests that social workers and others

need to intervene to ensure that the youth receive the health and financial support to which they are entitled and which make HIV treatment and other health services more accessible. The fact that those who had been seen by health service providers had better prior HIV testing behaviors and future testing plans indicates that improved access to healthcare may enhance participation in HIV testing (Ayiga et al., 2013; Manzo, 2010; Laura Nyblade et al., 2013).

Use media campaigns designed for this community especially using paid commercials on radio and television to promote the importance of HIV testing, specifically among the youth in their respective communities. Employ radio talk shows featuring community healthcare providers and patient testimonials.

Culturally-specific presentations regarding the HIV and AIDS epidemic designed to address awareness of HIV risk can help to overcome the negative impact of stigma on testing and treatment needs (Abrams & Hogg, 1988; Boswell & Baggeley, 2002; Church et al., 2015; Hobson, 2008). Encouraging the youth to speak up within communities about including HIV testing and seeking treatment in routine healthcare can build individual self-efficacy, while, providing a role model with whom the community can identify (Kharsany & Karim, 2016; Pinel, 1999; Ruggiero & Taylor, 1997; Scambler, 1998).

In addition, combining worldviews by putting these two together, a culturally relevant social work curriculum should address social issues of the time that are relevant to the cultures of the country. In practice, this implies culturally appropriate interventions that address contemporary social work issues and that support positive change in this particular country (Bartlett et al., 2001; Castro & Farmer, 2005; Simbayi et al., 2007; Ssekubugu et al., 2017). The two authors: Simbayi and Ssekubugu stated, “It involves the continuing evaluation of cultural practices in light of international, regional and national policies.”

Free community-based classes to improve the skills needed to access HIV testing may also help to lessen the barriers experienced by the youth. By making HIV-related materials available throughout the communities, at organizations, and at local businesses, community members will come to understand that protection from infection is part of community life (Macintyre et al., 2001; Ortblad et al., 2017; Russell et al., 2016). Community-based health fairs where information on the HIV and AIDS epidemic are shared may be particularly helpful in disseminating news about developments and policies on HIV testing. In addition, general community health education aimed



at improving health status through the promotion of healthy behaviors and altering those forces that adversely affect the health and well-being of community members, can take place during a health fair.

In this way, the youth may discover ways to overcome the barriers they encounter in accessing all health services. Perhaps including HIV among general health promotion activities can contribute to reducing HIV stigma and improving access to health care services (Batchelder, 2020; Beer et al., 2019; Farotimi et al., 2015; Rosengren et al., 2021).

The disparity in the HIV and AIDS disease burden of the youth in Kampala and the tendency for late HIV diagnoses among the youth in the country constitute a social justice issue and underscore the need among the youth for empowerment in all senses of the word (Adom & Asare-Yeboah, 2016; Ahmedani et al., 2013). Social workers can use the findings of this study in their work with the youth at risk of infection to encourage early HIV diagnosis and to ensure proper linkages to preventive and care services (Bonnington et al., 2017b; Ruria, 2017; Wouters, 2017). Some youth organizations can likewise use the findings reported here in their efforts to increase awareness, health service use, and individual healthy behaviors within their communities.

Both social workers and the youth have new resources for their advocacy work to address the disparities experienced by youth in Ugandan communities. As present research suggests, the youth are battling with denial and stigma associated with HIV infection, testing, and treatment in both their places of residence and in the country at large. A large portion of these youth may perceive themselves to be at low risk for HIV infection, despite engaging in high-risk behavior. This denial can arise for many reasons, including culturally specific fears and stigma associated with the infection. In light of such challenges, the use of empowerment precepts is indicated (Ayiga et al., 2013; Dytone Wella, 2015b; Kimera, Vindevogel, De Maeyer, et al., 2019b).

Once thought of as an urban disease, the prevalence of HIV and AIDS in the Ugandan communities is steadily increasing among the youth (Vreeman, 2017; Swahn et al., 2019a, 2021). AIDS in rural communities affects adolescents, the married, heterosexuals, and men and women from all lifestyles. The expansion and improvement of HIV and AIDS education programs in small communities around the world is critical to preventing the spread of HIV. There are an estimated 33 million living with the virus and each year millions more people become infected (Kimera et al., 2019a; Nyblade et al., 2009; Unaid, 2017). Therefore, effective HIV and AIDS educational

programs can help prevent these new infections by providing people with information about HIV and how it is passed on.

HIV programs are done by equipping individuals with the knowledge to protect themselves from becoming infected. An HIV and AIDS education program plays a vital role in reducing stigma and discrimination (Camlin et al., 2020). Around the world, there continues to be a great deal of fear and stigmatization of people living with HIV, which is fueled by misunderstanding and misinformation. This not only has a negative impact on people living with HIV, but can also fuel the spread of HIV by discouraging people from seeking testing and treatment.

HIV and AIDS education can be effective when targeted at specific groups who are particularly at risk of HIV infection, both in urban and rural communities. The groups that HIV and AIDS education needs to target vary, depending on the nature of the epidemic in an area. High-risk groups can also change over time (Dow et al., 2020a, 2020d, 2020b; Lancaster, 2018; Dzah, 2019). For example, in the early years of the AIDS epidemic in Uganda, men who had sex with men and injecting drug users were most at risk of HIV infection, yet they were unknown in the country.

Today, the heterosexual young women population is identified among groups particularly vulnerable to HIV infection in Uganda (Dow et al., 2020b). AIDS affects many parts of the society and so everyone needs to be aware of HIV and AIDS. However, it is important that such a focus does not lead to groups who are considered not at risk missing HIV and AIDS education. This can lead to a rise in HIV infection rates amongst groups who are neglected by HIV and AIDS education, for example older people.

Furthermore, AIDS affects many parts of society, and so everyone needs to be aware of HIV and AIDS. Providing the general population with basic AIDS education contributes to the spread of accurate information; promoting awareness and tackling stigma and discrimination (Church et al., 2015; Mehta & Quinn, 2016; Morolake et al., 2009). It is important that such people who are already infected with HIV receive HIV and AIDS education. This can help people to live positively without passing on the virus to anyone else; to prevent themselves becoming infected with a different strain of the virus and to ensure a good quality of life by informing them about medication and the support that is available to them (Lowther, 2018; Reif et al., 2021; Tsondai et al., 2017)

Health education campaigns should integrate a change from fear to care of people living with HIV and AIDS, especially among healthcare personnel (Feyissa et al., 2019; Vreeman, 2017). If we are to address the challenge of HIV stigma and prevention of HIV and AIDS among the youth, designed programs targeting psycho-social experiences of risk behavior will play a tremendous role (Quinn, 2017).

More and new innovative interventions, approaches, and techniques will continue to evolve, encompassing principles of youth development and being responsive to changes in social and biological factors, which substantially influence youths' health behaviors (Adekunle, et al., 2019; Bavel et al., 2020; Turan et al., 2017). Further research is needed to evaluate the role of culture, religion, and social structures, and their relationships to stigmatizing attitudes in various ethnic communities, which represent the two communities in Uganda.

### **8.7 Practical implication of the study**

Social workers are involved in direct service, research, agency leadership, and advocacy aspects in the HIV field. In all these roles, awareness of and utilizing the findings of this study can enhance the cultural appropriateness and the effectiveness of their work (Molloy et al., 2020; Peterson & Peterson, 2020). The public health community and the Government of Uganda can use the findings for their empowerment as community agents and for their own improved individual and community health status (Adam et al., 2021; AL Nguyen, 2018).

### **Way forward**

Effort should be made to promote the uptake of HIV testing among youth, social workers, motivated by social justice and empowerment goals, must address structural and social barriers to HIV testing, such as increasing access and enhancing awareness of risk factors (Bandiera et al., 2012; Kimera et al., 2019a; Nyblade et al., 2009; Ssekubugu et al., 2017). The youth in Uganda are often exposed to the mainstream ethnocentric worldview, which portrays them as inferior. By using an empowerment model, their collective sense of self-enhancement by exposing them to literature, video, and other images portray youth in a positive way.

## **8.8 Conclusion**

In conclusion, from the analysis, it is clear that stigma against the youth living with HIV and AIDS in Uganda exists. Secondly, stigma is a barrier to HIV prevention, care and treatment. Third, stigma has proved to be a barrier to HIV prevention, care and treatment. In order to mitigate the impact of HIV stigma and discrimination, effective strategies that encompass and involve all structures or levels of society, right from political leadership, to the common person in society be implemented. In addition, this study found out that lack of adequate HIV knowledge and information in some communities of Uganda is the root cause of HIV-related stigma. There is a need to integrate HIV information with human rights. In order to scale this up, youth living with HIV should be adequately involved in HIV prevention. There is a need for care and treatment efforts because they are a vital resource that is adequately facilitated and supported by the government and people in society.

Lastly, in the study I established that HIV and AIDS is not a straightforward phenomenon as attitudes towards the epidemic and those affected vary massively. Social workers play a big role in empowering the youth to take care of their health. Reactions to HIV and AIDS vary between individuals and groups of people. With that, AIDS-related stigma and discrimination change over time as infection levels, knowledge of the disease and treatment availability vary. Stigma and discrimination are the major obstacles of effective HIV and AIDS prevention and treatment in urban areas like Kampala city. HIV and AIDS-related stigma and the resulting discriminatory attitudes create an environment that fuels the epidemic. Stigma of HIV and AIDS is based on social, shared ignorance, fear and misinformation. This is particularly more intense in this part of Uganda, where an arguably poor health system entangled with a poor legal and ethical framework. The role of stigma and discrimination seems to be that of being a barrier to all essential components that make up good prevention and treatment programs. Social workers play a big role in empowering the youth to take care of their health.

## **8.9 Policy recommendations**

From the research questions, the findings that I came up with and the subsequent conclusions made the following recommendations:

Youth should be helped to understand that being HIV + is not the end of their lives. Both the youth and community should be helped to reduce fear of each other through the use of practical activities.

Encourage the youth to go for voluntary testing. Encourage the youth to seek treatment and care services. Social workers involved in direct service, research, agency leadership and advocacy aspects, should utilize the findings to enhance cultural appropriateness and effectiveness of their work. The education programs and risk reduction programs are provided in collaboration with local churches that provide interventions focusing on high risk heterosexual populations including young women, young men and other categories of populations in communities with support from the Clergy and Religious Community. It is believed that the religious values and the power of religious leaders of various sects to mobilize communities that can be used to design effective and sustainable community programs to address stigma which is associated with HIV. This implies how to involve the religious leaders in programs to eliminate the stigma and other forms of discrimination which are often directed to persons living with HIV and how to encourage community support and other health services. It is believed that the religious leaders have a task to promote a vibrant skillful collaboration to effectively deliver the services needed by the society. Their roles are unique and touch on all spheres of life. At best, religious leaders instruct, guide, encourage, correct, mediate and care for members of their faith communities through all aspects of life, including death.

Youth living with HIV and AIDS are taken by the desire to have children and ignore the status quo. Monitoring and evaluation is a requirement in such a program concerning the cultural norms of the communities. There is a need for a system to follow up on issues that are put forward by the community during sessions. Facilitators need access to expertise and update information in areas they are not trained. This could be either a resource center that has books, or videos, or posters that the facilitators can refer to or access to local experts like, nurses, doctors and counselors that can help them with the technical components of certain workshops (Ajong et al., 2018; Arinaitwe et al., 2021; Odimegwu et al., 2017).

Implementers of HIV and AIDS education programs cannot snap their fingers and make them happen, but they can work at it and get good community support. Community support has to come from a variety of corners, both the predictable and unexpected (Ortblad et al., 2017). Much as there is support and opposition for education implementation among the targeted population in terms of support, there are no AIDS designated centers for instance resource, voluntary, counseling and testing places.

The most compelling sources of support are people there who are targeted for and accept their status, for example people living with HIV and AIDS. The most obstacles in communities are unacceptable as human beings not as lepers. People in some communities are unwilling to talk about sexual abuse, sexually transmitted diseases, drug use, lesbianism, homosexuality, HIV, and AIDS issues. In some communities, not many people in the public eye of their respective places have spoken out about family members, although it is known that they exist. The stigma is still very great, which indicates there has not been much of an advance in public acceptance and support (Azia et al., 2016; Mitchell et al., 2020).

The stigma should not discourage people from working. The HIV and AIDS education programs provide mentoring for all participants. The role of the mentor is to inform participants about alternative available choices, for example activities and goals, familiarize them with strategies available for pursuing those choices, provide training, opportunities for practice, and feedback in the development of skills for implementing particular strategies.

In addition, there is a need to provide relationships through which participants are affirmed, inspired and encouraged to make healthy choices (Ajayi et al., 2019; Cawley et al., 2014). Use incentives such as gifts and special events to build morale and attachment to the pro-social goals of the program. Such programs include among others: gift certificates, trips and vouchers for pizza, sports shops, movies, and stipends for community services of HIV and AIDS education programs. As a proposed program of HIV and AIDS, education developed and ready for implementation, monitoring and review arrangements ensure ongoing assessments and evaluations and to undertake corrective measures if needed.

There is a need to develop policies beforehand. Don't adopt a "wait and see" approach (McKinnon & Vandermorris, 2019). The process of policy development, for instance, can help resolve disagreements and build consensus and support for HIV and AIDS programs. Involvement of the whole community; many educators agree that HIV education is more easily accepted, especially when the curriculum, materials and activities are developed locally, with the community's needs and values in mind (Sam-Agudu et al., 2019). Assessments should be done for what the community needs and who is at risk, then work with parents and other groups, including the religious leaders, to reach consensus.

Stigma reduction - there is a need to educate the public on the definition of stigma and emphasize issues such as the terms that people use for the infected and the infection itself that are stigmatizing to the infected individuals (Ajayi et al., 2021). These teachings should also emphasize HIV transmission, since findings have indicated overwhelming fear of HIV transmitted through casual contact. If possible, the teachings should be organized in a way that focuses on generalizing HIV infection as any other infections, since it is not everyone that has the infection that was engaged in promiscuous behaviors (Eisinger et al., 2019).

There is also an urgent need to involve families and communities including religious leaders at all levels in the fight against the disease and stigma since these people have an effect that can bring a positive change in the attitudes of the people they serve in their respective communities. Through their involvement, communities should be encouraged to discuss openly around sexuality, HIV and gender-related issues by building positive norms through community involvement in discussions about the same issues

#### **8.10 Suggested Areas for Future Study**

The researcher recommends that a similar study be done with a representative sample covering many districts in Uganda to strengthen the external validity. The areas for further study include the following:

This topic needs further interrogation due to the popularity of HIV in Kampala. Moreover, many youths (both male and female) in this study reported engaging in risky behaviors, believing that they were at risk for HIV infection. A more detailed study of the dissonance between the belief and behavior patterns of these participants explored.

The policies in Uganda regarding HIV and AIDS have proved to be very oppressive towards people living with HIV and AIDS. They are burdened with the responsibility of preventing further HIV infection while at the same time providing a false sense of security to the ‘normal’ members of society. This has been proved by the statistics indicating a rising number of HIV infections in Uganda over the years. Some even think it is worse than what the statistics reveal, given the high numbers of sero-status in Kampala Capital City Authority in Uganda.

Impact of HIV and AIDS on marriage life; there is need to explore the reasons for un-imputation of blame between men and women with regard to HIV infection.

HIV and AIDS scourge and ARV/ART treatment; there is a need to assess the impact of the anti-stigma programs that are put in place, such as the greater involvement of youth living with HIV and AIDS and other home-based care programs.

Public opinion and the spread of HIV and AIDS: There is a need for future research assessing the progress and impact of intervention of stigma and discrimination reduction. It is essential to adopt tools and indicators to measure stigma and discrimination.

Religion and control of the spread of HIV and AIDS: There is a need to explore the role of religious institutions in the fight against the HIV and AIDS epidemic.

### **Contribution to the study**

A stigma Treatment Seeking Behavior analytical framework has been developed from this study. Stigma has been identified as biggest barrier to fighting HIV and AIDS.

### **8.11 Limitations of the Study**

The researcher acknowledges the following inherent limitations in this study. First, the researcher's experience as a senior teacher and lecturer could have brought personal bias in the study. Second, it is assumed that all those who participated in the study gave honest responses basing on their personal views and experiences. Third, the data collected represented the perceptions and experiences of a limited number of participants. Lastly, the study was limited to the district of Kampala in Central Uganda.

Nevertheless, the researcher mitigated the effects of the above limitations by taking the following measures. First, the draft was given to several participants and some senior researchers for scrutiny. Second, the study protocol used to collect data was rich, and had provisions for triangulation to verify the data. Third, data was systematically coded and iteratively compared within and across all the participating health units. Fourth, the use of more than one health unit as well as a large sample size enhanced the statistical generalization of results to the broader theory of HIV stigma treatment seeking behavior.



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## **APPENDICES**

### **Appendix I: Interview Guide for Youth**

Thank you for agreeing to participate in this research interview. First, I would like to remind you that everything in our interview will be treated with confidentiality and respect. The research will most benefit from your truthful and honest responses to each question and from our open discussion. Second, I want to remind you that the interview will be audio - tape-recorded. The tape recording will also be kept confidential. In addition, I would like to remind you that you are totally free to answer any questions, to answer some and not others, or to continue or end the interview at any time. Of course, the more honestly and completely you complete the interview with me, the more valuable your participation will be.

**Date of interview:**

**Study site:**

**Code Number:**

**Questions**

**Demographic Data:**

**Objective One: Perception of stigma among the youth**

**HIV Diagnosis**

1. Please, tell me how long you been living with HIV? Probe for who told you (health care provider) and what motivated you to go and test?
2. Would you please tell me how your life has been like since you were diagnosed having HIV and AIDS?

*Probe for: Are you selective with who you tell?*

- Family
- Friends

- Health care providers
- Community
- How do people react when you tell them you are HIV-positive?
- Why/why not keep it a secret?

### **Stigma about HIV and Health seeking behavior**

3. Please, tell me what it means to you having HIV and AIDS?

Probe for: what do others say or think of what having HIV and AIDS is.

- Family members,
- Friends
- Health workers
- Community

4. Have you experienced any social interaction changes when you knew about your status?

If yes, would you mind share the experiences with me? *Probe for: before onset of symptoms during the time that symptoms started showing how did they manage to cope with it?*

5. How have the following been of assistance to you? Family members, friends, employer, community support group, church, community and health facility

6. Comparing **life/experiences** before or after HIV diagnosis, what's different or the same in relation to the following?

- How you think of yourself
- Health care and treatment
- Family
- Community
- People you work with

7. Are there any positive events that have helped sustaining your life since the time you were diagnosed with HIV and AIDS? *If yes, probe for the events and their contribution.*

8. Do you know of any one or group of people who have not helped to live positively since time you were diagnosed with HIV/AIDS? *Probe for those people or group of people and their influence.*
9. How has been your **health** been since you were diagnosed with HIV/AIDS? If any hospitalizations, *probe for where he or she goes for treatment and care, how they know about the HIV treatment and care and the nature of treatment and care and how often he or she access HIV treatment and care.*

If no hospitalizations, probe for why he or she has not sought treatment and care from the health providers

### **General Overview**

In your overall assessment of living with HIV and AIDS, which aspects do you think are supportive or not supportive, working well in relation to treatment and care and those that needs to be improved for the youths.

## **Appendix II: Interview guide for Key Participants (Health workers, Parents and Teachers)**

1. Through your encounter with the youths living with HIV/AIDS, please tell me about HIV treatment and care for the youth? *Probe for available opportunities of youth for HIV testing, treatment and care services in the community*
2. Are you satisfied with HIV treatment and care services for youth in your community? If no, would you share the reasons why? *Probe for HIV stigma and discrimination*
3. Would you explain to me what HIV/AIDS means to you? *Probe for what he or she think about HIV /AIDS, what others people think about HIV/AIDS? And the implications to HIV treatment and care for the youth*
4. Evidence has shown that PLWHA face negative reactions from people close to them and other members of the community (family, friends, health providers and the community). Does this happen to some of the youth living with HIV PLWHA in this community? *If yes, probe, extent of the problem, the reasons why people do this and the implications to HIV treatment and care.*
5. Are there HIV treatment and care services for youth you know of in this community? If yes probe for the nature of services, the providers and level of utilization by the youth.

### **Appendix III: In depth case study interview guide for selected youth**

1. What has changed since HIV was initially identified in the country
2. Was there much fear about contracting HIV; and what is the situation now?
3. What are the most common experiences of youth that contract HIV?
4. How often do you feel isolated from the community after learning you have HIV and AIDS
5. What are most frequently encountered practices that reflect?
  - a) Negative behavior
  - b) Feelings
  - c) Thinking



#### Appendix IV: Focus Group Discussions Guide for the youth living with HIV

1. There are a lot of things people say about PLHIV. What do people in this community say about them?

*(Probe for what people say about the young people (youths) who have HIV).*

2. Now let us talk about the **forms of stigma and discrimination** of PLHIV in your area. In your view, what forms of HIV related stigma are prevalent in your area?

Probe for;

- *Exclusion from community gatherings (e.g. weddings, funerals, parties, clubs)?*
- *Exclusion from religious activities or places of worship*
- *Exclusion from family activities (e.g. cooking, eating together, sleeping in the same room?)*
- *Exclusion from work related activities (employment, promotion, functions etc.)*
- *Gossiped about within the community*
- *Subjected to abuse (physical, verbal, psychological)*
- *Sexual rejection*

3. Of the above forms of stigma and discrimination, which ones are more prevalent to youth living with HIV in this community? *Probe for which group of people mostly perpetuate these forms of stigma and discrimination*
4. Now let us talk about your HIV related Stigma and health seeking behavior. Do HIV stigmas affect health-seeking behavior of the youth in this community? Yes/No. If yes, could you provide the ways HIV stigma has affected the youth living with HIV to seek health services in this community?
5. Please tell us how have the following have been of assistance to youths living with HIV? Family members, friends, employer, community support group, church, community and health facility.
6. Is there any way (s) you have helped a youth living with HIV in this community? *If yes, probe for the support rendered.*

7. In your own views do you think the youth living with HIV in this community are now comfortable or safe to disclose their status?

*Probe for:*

*(a) If Yes/No. Why do you think are they comfortable or uncomfortable?*

*(b) What are the personal experiences you have personally had or witnessed within the society?*

Comment on

- The achievements
- The challenges of some the treatment services
- What is your view on how to make such services friendly?

### **General Overview**

In your overall assessment of living with HIV/AIDS, which aspects do you think are supportive or not supportive, working well in relation to treatment and care and those that needs to be improved for the youths.

## **Appendix V: Consent to participate in Research (Youths)**

**Project Title:** The effect of stigma among youths living with HIV and AIDS

**Researcher(s):** Anthony Kiwanuka

**Faculty Sponsor:** Social Sciences/Department of Social Work

### **Introduction**

I am Anthony Kiwanuka, a PhD student. I am conducting a research study on: **The effect of stigma among youth living with HIV and AIDS**

You are being asked to participate because you are between the ages of 18 and 24 years of age with an HIV positive status. You are one of 22 youths who are being selected for this study. Please read this form carefully and ask any questions you may have before deciding whether to participate in the study.

### **Purpose**

The purpose of this study is to understand more about stigma among youth who are HIV positive. Your participation will help us to identify gaps and needs in providing services, specific to your community. It will also help us to improve services and programs for other youths living with HIV and AIDS. In case of some break down of participants during the course of the study, the medical personnel will be sought for help.

### **Procedures**

If you agree to be in the study, I will ask you questions pertaining to your life before and after testing positive for HIV. The research will be conducted through one interview session in a private and confidential room in the clinic. It is anticipated that the research interview will take approximately one hour of your time. Research questions will include general demographic questions, and questions related to your experience with HIV and AIDS. You will be asked to describe your experiences, including difficulties you faced, support you have received before and after testing HIV positive, and how you have managed your life since your diagnosis. These

interviews will also be audio recorded. The interviews will take place at a location that makes you feel comfortable and is convenient for you.

### **Risks/Benefits**

This study asks you to share your story about how you felt after knowing your HIV status and your personal experience. You may feel uncomfortable with some of the questions included in this research. You can refuse to answer any question for any reason and/or skip any questions that you don't want to answer. You can stop your participation in the research at any time without any consequences. The likely benefits to you are minimal; however, the overall impact for your community could be significant because new information related to HIV and AIDS services in your community will become available to address this important health problem.

### **Confidentiality**

Each interview will be coded to maintain strict confidentiality. You will not be identified with the information that you give. Your name will not appear on the interview tape and any information you give will be given a code. The researcher will be the only person that has a list of the names and their corresponding codes: this will be kept secure, so no one else will have access to it. These tapes will be destroyed when the research project is over. We will not use your name when we report results of the interviews.

### **Voluntary Participation**

Participation in this study is voluntary. If you do not want to be in this study, you do not have to participate. Even if you decide to participate, you are free not to answer any question or to withdraw from participation at any time without penalty. Either your participation or non-participation will not have any impact on services from the Health care center.

### **Contacts and Questions**

If you have questions about this research study, please feel free to contact Anthony Kiwanuka P.O. BOX 7 KISUBI.

+256 772 950434 akiwanuka@gmail.com/akiwanuka@chuss.mak.ac.ug

If you would like to talk to someone other than the researcher(s) about; (1) concerns regarding this study, (2) research participant rights, (3) research – related injuries, or (4) other human participants ‘issues, please contact:

The Chair

Makerere School of Social Sciences

Research Ethics Committee.

Telephone +256 772 457576 E-mail: sheisim@yahoo.com

Or

The Executive Secretary

The Uganda National Council of Science and Technology,

Kimera Road. Ntinda P.O. BOX 6884 Kampala, Uganda

Telephone: +256 414-234579

E- mail: info@uncst.go.ug

### **Statement of Consent**

I have read the above information or had the information read to me. I have received answers to the questions I have asked. I consent to participate in this research. I am at least 18 years of age. Your verbal acknowledgement indicates that you understand the information provided above, have had an opportunity to ask questions, and agree to participate in this research study.

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***Participant’s Signature***

---

***Date***

---

***Researcher’s Signature***

---

***Date***

## **Appendix VI: Okukkiriza okwetaba mu kunoonyereza (Abavubuka)**

### **Omutweogw'Okunoonyerezako: ENKOVU (stigma) MU BAVUBUKA, EZIVA MU KUBEERA N'AKAWUKA KA MUKENENYA**

**Anoonyereza:** Anthony Kiwanuka

#### **AwagiddeOmulimo**

##### **Ennyanjula**

Osabibwa okwetaba mu kunoonyereza okukolebwa Anthony Kiwanuka nga owandiika ku Mutwe ogwo waggulu, nga Ekitongole kya Ssetendekero e Makerere, Kampala, Ekyembeera z'Abantu kye kimulabirira.

Osabibwa okwetaba mu kunoonyereza kuno kuba oli mu myaka 18 okutuuka ku 24 egirinaakawuka ka mukenenya (HIV). Ggwe omu ku bantu amakumi abbiri mwa babiri (22), abavubuka abaloneddwa okwetaba mu kunoonyereza kuno. Osabibwa osome bulungi olupapula luno, bw'oban'ekibuuzo okibuuze, osoble okwanukulwa obang'oneetaba mu kunoonyereza kuno.

##### **Ekigendererwa**

Okunoonyereza kuno kugendereddwamu okutegeera ebizibu, naddala enkovu (stigma) eziva mu kubeera n'akawuka ka Mukenenya, mu bavubuka. Okwetaba mu kunoonyereza kuno kujja okuyamba okuzuula emiwaatwa n'obwetaavu mu mpeereza y'okulabirira abantu abalinga ggwe, naddala mu kitundu gy'obeera. Era kujja kuyamba n'okulongoosa endabirira y'abavubuka abalala abali mu bitundu ebirala, nga nabo abalina Akawuka ka Mukenenya, n'abalina Mukenenya.

##### **Enkola**

Bw'oba okkirizzao kwetaba mu kunoonyereza kuno, waliwo ebibuuzo by'ojja okwanukula nga bikwata ku mbeera gyewalimu nga tonnaba kumanya nti olina akawuka, ate n'oluvannyuma lw'okuzuulanga akawuka okalina. Okunoonyereza kujja kukolebwa ng'obuuzibwa ebibuuzo, mu kafo akesiifu mu *kirinika*, bino bijja kuba byamulundi gumu. Kino kijja kutwala ekiseera ekitasukka ssaawa emu n'ekitundu. Ebibuuzo bijja kubeeramu ebyo ebikwata ku kitundu gy'obeera, ne by'olabye ku Kawuka ka Mukenenya. Ojja kubuuzibwa by'oyiseemu, nga obuzibu

bw'osanze, okubudabudibwa kw'ofunye, ng'ogeranya nga tonnaba kumanya nti olina akawuka n'oluvannyuma lw'okumanya ng'okalina, n'engeri gy'okuttemu embeeraeyo, okuva lwewekebeza n'omanya embeera gy'olimu. Eddoboozilyo lijja kukwatibwa ku lutambi/akayinja (disc). Naye bino bijja kukolebwa mu kifo gy'owulirira emirembe, nga wesiifu.

### **Obuzibu/ebirungiebirimu**

Mu kunoonyereza kuno osabibwa okugabanya ku by'oyiseemu okuva lwewamanya ng'olina akawuka ka mukenenya. Ebibuuzo ebimu biyinza okubanga tebikuyisa bulungi mu kwanukula. Oyinza obutabyanukula. Oba oyinza okusalawo, obudde bwonna, okuva mu kunoonyereza kuno, ng'oliwaddembe. By'oyinza okufunamu kululwo biyinza okuba ebitono, naye ekibiina ky'abantu b'obeera nabo kiyinza okuganyulwa ennyo kubikwatagana n'endabirira y'obulamu bw'abantu abalina akawuka ka mukenenya.

### **Byakyama**

Buli muntu anabuuzibwa, ebimufaako ng'omuntu, bijja kukisibwa nnyo: buli omu ajja kuweebwa akabonero ke, nga tewali ayinza kumanya nti gundi ye yayogera bino. N'erinnyalyo terijja nakulabikako ku katambi/kayinja. Entambi zijja kusaanyizibwawo ng'omulimo guwedde, ne mu lipoota erinnyalyo teririrabikamu.

### **Okwetabamu kwakyeyagalire**

Okwetaba mu kunoonyereza kuno kwakyeyagalire. Bw'oba toyagala, tewetabaamu. Ne bw'oba osoose okwetabamu oli waddembe ebibuuzo ebikukaluubiridde okubireka, n'okubiviramu ddala byonna awatali kuvunaanibwa. Obuteetabamu oba okwetabamu tekijja kukosa mpeereza eri abantu abakwatibwako.

### **Endagiriron'ebibuuzo**

Bw'oba olina ky'obuuzo ku kunoonyereza kuno, tuukirira

Anthony Kiwanuka, P.O. BOX 7 KISUBI.

+256 772 950434 ng'oyita ku ndagiro y'omutimbagano

eno: akiwanuka@gmail.com/akiwanuka@chuss.mak.ac.ugoba Ab'Ekitongole e Makerere.

N'ensonga ezidda kuddembelyo oyinza okuzitwala eri

The Chair  
Makerere School of Social Sciences  
Research Ethics Committee.  
Telephone +256 772 457576 E-mail: sheisim@yahoo.com  
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The Executive Secretary  
The Uganda National Council of Science and Technology,  
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**Okukkiriza**

Ekigambokyo kitegeeza nti ebiri waggulu obitegedde, era nti ofunye omukisa okubuuza ebibuuzo by'oyagala, kati okkirizza okwetaba mu kunoonyerezakuno.

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***Omukono gw'Eyetabye mu kunoonyereza***

---

***Date***

---

***Omukono gw'Anoonyereza***

---

***Date***



## **Appendix VII: Consent to participate in Research (Key participants)**

**Researcher(s):** Anthony Kiwanuka  
P. O. BOX 7Kisubi  
Tel. +256 772 950434  
Email: akiwanuka@gmail.com

**Project Title:** “Stigma and HIV and AIDS treatment seeking behavior among youth living with HIV in Kampala”

### **Introduction:**

I am Anthony Kiwanuka, a PhD student. I am conducting a research study on “**Stigma and HIV and AIDS treatment seeking behavior among youth living with HIV in Kampala**” I am a self-sponsored student.

### **Purpose**

The purpose of this study is to understand more about stigma among youths who are HIV positive. Your participation will help us to identify gaps and needs in providing services, specific to your community. It will also help us to improve services and programs for other youths living with HIV and AIDS. This study will have 15 participants from various categories.

### **Procedures**

You have been selected as a key informant for this study. Please read this form carefully and ask any questions you may have before deciding whether to participate in the study.

If you agree to be in the study, I will ask you questions pertaining to your experiences with youth living with HIV and AIDS. The research will be conducted through one interview session in an environment convenient to you. It is anticipated that the research interview will take approximately one hour of your time. Research questions will include general demographic questions, and questions related to your experience with HIV and AIDS youth. These interviews will also be audio recorded.

**Risks/Benefits**

The study will have minimal risks, for example you may feel uncomfortable answering some questions. I don't want this to happen but if it does you are free to answer or skip any questions that you don't want to answer. You may not benefit directly as an individual: however, the overall impact for your community could be significant because new information related to HIV and AIDS services in your community will become available to address this important health problem.

**Confidentiality**

Each interview will be coded to maintain strict confidentiality. You will not be identified with the information that you give. Your name will not appear on the interview tape and any information you give will be given a code. The researcher will be the only person that has a list of the names and their corresponding codes: this will be kept secure, so no one else will have access to it. These tapes will be destroyed when the research project is over. We will not use your name when we report results of the interviews.

**Voluntary Participation**

Participation in this study is voluntary. If you do not want to be in this study, you do not have to participate. Even if you decide to participate, you are free not to answer any question or to withdraw from participation at any time without penalty. Your participation or non-participation will not have any impact on services from the health care center.

**Treatment**

In case of some break down of participants during the course of the study, the counselor/medical personnel will be sought for help.

**Compensation/reimbursement**

The participants will be given Ug. Shs. 10,000.00 for transport and Ug. Shs. 5000.00 for refreshment (water, soda, cakes)

**Ethical clearance**

Has been approved by Makerere University School of Social Sciences Research Ethics Committee (MAKSS/REC) and Uganda National Council of Science and Technology

## **Dissemination**

Feedback will be given to all participants on findings about the study in terms of conferences and presentations at local, national and international levels. All the findings and policy briefs to all concerned participants will be disseminated. Materials tailored to different categories of participants will be distributed and a copy given to individual participants in this study in a timely manner at a free cost. For purposes of youth living with HIV and AIDS, the researcher will go back to the different young youth and share feedback with those that got involved in the study and materials will be simple and the researcher will take time to explain to the youth living with HIV in Kampala, in the best language possible the outcomes of the study.

## **Contacts and Questions**

If you have questions about this research study, please feel free to contact Anthony Kiwanuka P.O. BOX 7 KISUBI.

+256 772 950434 akiwanuka@gmail.com/akiwanuka@chuss.mak.ac.ug

If you would like to talk to someone other than the researcher(s) about; (1) concerns regarding this study, (2) research participant rights, (3) research – related injuries, or (4) other human participants' issues, please contact:

The Chair

Makerere School of Social Sciences

Research Ethics Committee.

Telephone +256 772 457576 E-mail: sheisim@yahoo.com

Or

The Executive Secretary

The Uganda National Council of Science and Technology,

Kimera Road. Ntinda P.O. BOX 6884 Kampala, Uganda

Telephone: +256 414-234579

E- mail: info@uncst.go.ug

**Statement of Consent**

I have read the above information or had the above information read to me. I have received answered to the questions I have asked. I consent to participate in this research. I am at least 18+ years of age.

*Name of Participant*

*Participant's Signature or thumbprint/mark*

*Date*

*Name of person obtaining consent: .....*

*Date*

*Name of witness .....*

*Signature or thumbprint/mark of witness: .....*

*Date*

## **Appendix VIII: Okukkiriza okwetaba mu Kunoonyereza (Abantu abeesigwa)**

**Omutwegw'Okunoonyerezako: *enkovu* (stigma) mu bavubuka, eziva mu kubeera n'akawuka ka mukenenya**

**Anoonyereza:** Anthony Kiwanuka

**Awagidde Omulimo**

**Ennyanjula**

Osabibwa okwetaba mu kunoonyereza okukolebwa Anthony Kiwanuka ng'awandiika ku Mutwe ogwo waggulu, nga Ekitongole kya Ssetendekero e Makerere, Kampala, Ekyembeera z'Abantu kye kimulabirira.

Ggwe omu ku bantu ekikumi mw'asatu mu babiri (15), abaloneddwa okwetaba mu kunoonyerezakuno. Osabibwa osome bulungi olupapula luno, bw'oba n'ekibuuzo okibuuze, osobole okwanukulwa oba ng'oneetaba mu kunoonyereza kuno.

**Ekgendererwa**

Okunoonyereza kuno kugendereddwamu okutegeera ebizibu, naddala *enkovu* (stigma) eziva mu kubeera n'akawuka ka Mukenenya, mu bavubuka. Okwetaba mu kunoonyereza kuno kujja okuyamba okuzuula emiwaatwa n'obwetaavu mu mpeereza y'okulabirira abantu abalinga ggwe, naddala mu kitundu gy'obeerera. Era kujja kuyamba n'okulongoosa endabirira y'abavubuka abalala abali mu bitundu ebirala, nga nabo abalina Akawuka ka Mukenenya, n'abalina Mukenenya.

**Enkola**

Bw'oba okkirizza okwetaba mu kunoonyereza kuno, waliwo ebibuuzo by'ojja okwanukula nga bikwata ku mbeera y'abavubuka abalina akawuka, oluvannyuma lw'okuzuula nga akawuka bakalina. Okunoonyereza kujja kukolebwa ng'obuuzibwa ebibuuzo, mu kafo akesiifu kowuliriramu emirembe, bino bijja kuba byamulundi gumu. Kino kijja kutwala ekiseera ekitasukka ssaawa emu n'ekitundu. Ebibuuzo bijja kubeeramu ebyo ebikwata kukitundu gy'obeerera, ne by'olabye kubavubuka abalina akawuka ka Mukenenya. Ojja kubuuzibwa by'oyiseemu, nga obuzibu bw'osanze, okubudabudibwa kw'abavubuka, ng'ogeranya nga tebannaba kumanya nti balina akawuka n'oluvannyuma lw'okumanya ng'abalalina, n'engeri gyebakuttemu embeera eyo, okuva lweeekebeza n'okumanya embeera gyebalimu. Eddoboozilyo lijja kukwatibwa

kulutambi/akayinja (disc).Naye bino bijjakukolebwa mu kifo gy'owulirira emirembe, nga wesiifu.

### **Obuzibu/ebirungiebirimu**

Mu kunoonyereza kuno osabibwa okugabanya endowoozayo kubavubuka abalina akawuka ka mukenenya.Ebibuuzo ebimubiyinza okubanga tebikuyisa bulungi mu kwanukula.Oyinza obutabyanukula.Oba oyinza okusalawo, obudde bwonna, okuva mu kunoonyereza kuno, ng'oli waddembe.By'oyinza okufunamu kululwo biyinza okuba ebitono, naye ekibiina ky'abantu b'obeeranabo kiyinza okuganyulwa ennyo kubikwatagana n'endabirira y'obulamu bw'abantu abalina akawuka ka mukenenya.

### **Byakyama**

Buli muntu anabuuzibwa, ebimufaako ng'omuntu, bijja kukisibwa nnyo: buli omu ajja kuweebwa akaboneroke, nga tewali ayinza kumanya nti gundi ye yayogera bino. N'erinnyalyo terijja nakulabikako kukatambi/kayinja.Entambi zijja kusaanyizibwawo ng'omulimo guwedde, ne mu lipoota erinnyalyo teririrabikamu.

### **Okwetabamukwakyeyagalire**

Okwetaba mu kunoonyereza kuno kwakyeyagalire.Bw'oba toyagala, teweetabaamu.Ne bw'oba osoose okwetabamu oliwaddembe ebibuuzo ebikukaluubiridde okubireka, n'okubiviramu ddala byonna awatali kuvunaanibwa.Obuteetabamu oba okwetabamu tekijja kukosa mpeereza eri abantu abakwatibwako.

### **Endagiriron'ebibuuzo**

Bw'oba olina ky'obuuzo ku kunoonyereza kuno, tuukiirira

Anthony Kiwanuka, P.O. BOX 7 KISUBI.

+256            772            950434            ng'oyita            kundagiriro            y'omutimbagano  
eno: akiwanuka@gmail.com/akiwanuka@chuss.mak.ac.ugobaAb'Ekitongole e Makerere.  
N'ensonga ezidda ku ddembelyo oyinza okuzitwala eri

The Chair

Makerere School of Social Sciences

Research Ethics Committee.

Telephone +256 772 457576 E-mail: sheisim@yahoo.com

Or

The Executive Secretary

The Uganda National Council of Science and Technology,

Kimera Road. Ntinda P.O. BOX 6884 Kampala, Uganda

Telephone: +256 414-234579

E- mail: info@uncst.go.ug

**Okukkiriza**

Ekigambo kyo kitegeeza nti ebiri waggulu obitegedde, era nti ofunye omukisa okubuuza ebibuuzo by'oyagala, kati okkirizza okwetaba mu kunoonyereza kuno.

---

***Omukono gw'Eyetabye mu kunoonyereza***

---

***Date***

---

***Omukono gw'Anoonyereza***

---

***Date***

**Appendix IX:           Consent to participate in Research**

**Project Title:**           The effect of stigma among youths living with HIV and AIDS

**Researcher(s):**       Anthony Kiwanuka

**Faculty Sponsor:**    Social Sciences/Department of Social Work

**Introduction**

I am Anthony Kiwanuka, a PhD student. I am conducting a research study on **“The effect of stigma among youths living with HIV and AIDS”**

You are being asked to participate in a case study because you are between the ages of 18 and 24 years of age with an HIV positive status. You are one of 22 youth who are being selected for this study. Please read this form carefully and ask any questions you may have before deciding whether to participate in the study.

**Purpose**

The purpose of this study is to understand more about stigma among youths who are HIV positive. Your participation will help us to identify gaps and needs in providing services, specific to your community. It will also help us to improve services and programs for other youths living with HIV and AIDS.

**Procedures**

If you agree to be in the study, I will ask you questions pertaining to your life before and after testing positive for HIV. The research will be conducted through one interview session in an environment of your convenience. Research questions will include general demographic questions, and questions related to your experience with HIV and AIDS. You will be asked to describe your experiences, including difficulties you faced, support you have received before and after testing HIV positive, and how you have managed your life since your diagnosis. These interviews will also be audio recorded.

**Risks/Benefits**

This study asks you to share your story about how you felt after knowing your HIV status and your personal experience. You may feel uncomfortable with some of the questions included in this research. You can refuse to answer any question for any reason and/or skip any questions that you



don't want to answer. You can stop your participation in the research at any time without any consequences. The likely benefits to you are minimal; however, the overall impact for your community could be significant because new information related to HIV and AIDS services in your community will become available to address this important health problem. In case of some break down of participants during the course of the study, the medical personnel will be sought for help.

### **Confidentiality**

Each interview will be coded to maintain strict confidentiality. You will not be identified with the information that you give. Your name will not appear on the interview tape and any information you give will be given a code. The researcher will be the only person that has a list of the names and their corresponding codes: this will be kept secure, so no one else will have access to it. These tapes will be destroyed when the research project is over. We will not use your name when we report results of the interviews.

### **Voluntary Participation**

Participation in this study is voluntary. If you do not want to be in this study, you do not have to participate. Even if you decide to participate, you are free not to answer any question or to withdraw from participation at any time without penalty. Either your participation or non-participation will not have any impact on services from the health care center.

### **Contacts and Questions**

If you have questions about this research study, please feel free to contact Anthony Kiwanuka P.O. BOX 7 KISUBI.

+256 772 950434 akiwanuka@gmail.com/akiwanuka@chuss.mak.ac.ug

If you would like to talk to someone other than the researcher(s) about; (1) concerns regarding this study, (2) research participant rights, (3) research – related injuries, or (4) other human participants' issues, please contact:

The Chair

Makerere School of Social Sciences

Research Ethics Committee.

Telephone +256 772 457576 E-mail: sheisim@yahoo.com

Or

The Executive Secretary

The Uganda National Council of Science and Technology,

Kimera Road. Ntinda P.O. BOX 6884 Kampala, Uganda

Telephone: +256 414-234579

E- mail: info@uncst.go.ug

**Statement of Consent:**

Your verbal acknowledgement indicates that you understand the information provided above, have had an opportunity to ask questions, and agree to participate in this research study.

---

*Participant's Signature*

---

*Date*

---

*Researcher's Signature*

---

*Date*

## Appendix X: List of Publications and Accepted Articles

### REVIEW PAPER

## Impact of stigma on HIV treatment seeking behavior among the youth living with HIV and AIDS in sub-Saharan Africa: critical review of literature

Anthony Kiwanuka<sup>1</sup>, Eddy Walakira<sup>1</sup>, Lena Andersson<sup>2</sup>, David K. Mafigiri<sup>1</sup>

<sup>1</sup>Makerere University, Uganda

<sup>2</sup>Gothenburg University, Sweden

### Abstract

An estimated 11.8 million youths in sub-Saharan Africa are living with HIV and AIDS, and more than one-half of those newly infected with HIV today are between 18 and 24 years. This study reviewed research assessing the impact of stigma on HIV treatment seeking behavior among youths in sub-Saharan Africa. The review highlighted particular stigma issues that young people face. Also, it analyzed the causes and consequences of stigma, and identified skills to cope with stigma and to build modalities for a change of behavior. The review include original articles published between 1988 and 2019 on HIV and AIDS stigma, which were found on various internet sites. The review determined that in developing countries, social and economic factors have an impact on HIV infection, including mainly older grandparents and their role as caregivers of orphaned children as a result of parental HIV infection. Therefore, there is a need to incorporate culturally sensitive modalities that assure target populations' ability to respond to local understandings of key issues associated with HIV and AIDS stigmatization. Stigma among the youth remains a barrier to all essential components, which constitute a good prevention program, and much detailed research on stigma reduction is required to improve components of a good prevention program. Health education campaigns should integrate a change from fear to care for people living with HIV/AIDS, especially among healthcare personnel. More prevention activities should be situated in rural and remote areas of each country than in urban locations, as currently in Nigeria. Since most of the population resides in rural areas, it is most appropriate to concentrate these programs in such locations.

HIV AIDS Rev 2021; 20, 2: 90-95  
DOI: <https://doi.org/10.5114/hivar.2021.107219>

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**Key words:** stigma, HIV and AIDS, treatment, youth.

### Introduction

Over a billion young people are living with HIV and AIDS worldwide, with 23.5 million found in sub-Saharan Africa [1]. The impact of stigma on youths has many consequences, including forced isolation, dropping out of school, and postponement of

starting antiretroviral treatment, prescribed to HIV-positive patients. Such challenges may hinder the access to HIV treatment [2].

Globally, stigma is a major obstacle to effective HIV and AIDS prevention and care. Stigma, in the context of HIV and AIDS, is a unique factor compared to other infectious

**Address for correspondence:** Anthony Kiwanuka,

Makerere University, Uganda, e-mail: [akiwanuka@gmail.com](mailto:akiwanuka@gmail.com)

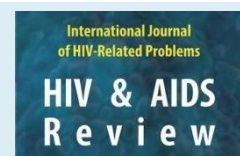
#### Article history:

Received: 06.08.2019

Received in revised form: 13.08.2020

Accepted: 28.09.2020

Available online: 30.06.2021



## Barriers of HIV Treatment-Seeking Behavior among Youths Living with HIV in Uganda: A Qualitative Study

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### Type

Research paper

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### Keywords

Treatment, HIV, youth, Uganda, seeking Behavior

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### Abstract

#### Background

This study aimed to explore experienced barriers to seek HIV treatment and care among the youth living with HIV and AIDS in Uganda. Given that the youth remain at the center of HIV epidemic, the study's ultimate goal was to contribute to the improvement of effectiveness of HIV prevention interventions for youth in Uganda. Twenty in-depth interviews were conducted with HIV-infected youth aged between 18 and 24 and who had entered care within one year upon receipt of results and referral for free care. In addition, key-informant interviews were conducted with 30 health service providers. The study used thematic content analysis to analyze the findings. The study found out that barriers to using HIV care included fear of rejection and HIV disclosure, young men and women's lack of support from their families; demanding work schedules, and high transport costs. Programmatic barriers included fear of rejection, antiretroviral drug side effects, long waiting and travel times, and inadequate service providers respect for patients. The study recommends targeted interventions to combat stigma, strengthen couple counseling and health education programs, and address gender inequalities among other things.

#### Material and methods

We conducted 20 in-depth interviews among HIV-infected individuals aged 18–24 years and Key informant interviews

#### Results

Barriers to using HIV care included fear of rejection and HIV disclosure, young men and women's lack of support etc.

#### Conclusions

Targeted interventions to combat stigma, strengthen couple counseling and health education programs, address gender inequalities, and implement youth-friendly and flexible clinic service hours are needed to address barriers to HIV clients.



### Experiences And Ways PLWHA Deal With Their Lives.

Journal:	<i>African Health Sciences</i>
Manuscript ID	WKR0-2019-11-1401.R1
Manuscript Type:	Original Article
Date Submitted by the Author:	10- Mar -2021
Complete List of Authors:	Kiwanuka, Anthony; Makerere University College of Humanities and Social Sciences, Social Work and Social Administration ; Uganda Christian University, Social work and Social Work Administration Walakira, Eddy ; Makerere University College of Humanities and Social Sciences, Social Work and Social Administration Mafigiri, David; Makerere University, Social Work and Social Administration
Keywords:	Health Behavior, Health services seeking,, persons living with HIV

SCHOLARONE™  
Manuscripts

# Unifying social work and faith - based communities in combating stigma: Social Work paper

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## Type

Review paper

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## Keywords

Transformation, interconnection, stand shoulder to shoulder, heart to heart in the fight against HIV and AIDS - related stigma

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## Abstract

Stigma is widely experienced and recognized as a major factor that facilitates the spread of HIV and AIDS epidemic. Unifying social-work skills and knowledge base with faith-based organizations or communities can contribute to combating HIV and AIDS and its stigma. Political actions, religious influence, societal engagement and openness are major modalities that combat stigma and assist prevention efforts. The issue of HIV and AIDS is both problematic and dangerous to affected individuals along social, economic, political and spiritual arenas. The problem is spreading rapidly among the younger generations around the world. It is a societal challenge to overcome HIV and AIDS and stigma. There is a great need of courage, commitment and leadership at all levels, mainly among religious leaders, to make a difference in the course of the epidemic. They are in a position of authority and able to use the trust in their respective communities to make change in the course of the scourge. They have the authoritative means for effectively fighting the HIV and AIDS stigma. This article will offer examples and modalities for combating HIV and AIDS related to stigma in society by using church leaders. They and their respective institutions possess strengths, credibility and are well grounded in communities. Leaders of the church have opportunities to make a practical and real difference in battling the stigma related to HIV and AIDS. The challenges of stigma experienced by individuals affected by HIV and AIDS calls for faith communities to act as a strong force for transformation

## Appendix XI: Introductory Letter -Makerere University Kampala

**MAKERERE**

P.O. Box 7062,  
Kampala, Uganda  
Cables: MAKUNIKA



**UNIVERSITY**

Tel: 256-41-545040/0712 207926  
Fax: 256-41-530185  
E-mail: makssrec@gmail.com

**COLLEGE OF HUMANITIES AND SOCIAL SCIENCES  
SCHOOL OF SOCIAL SCIENCES  
RESEARCH ETHICS COMMITTEE**

Your Ref:

Our Ref: MAKSS REC 01.18.117

29<sup>th</sup> March 2018

**Anthony Kiwanuka**  
**Principal Investigator (MAKSS REC 01.18.117)**  
**Makerere University, School of Social Sciences**  
**P O Box 7062**  
**Tel: +256 772 950434**  
**Email: [akiwanuka@gmail.com](mailto:akiwanuka@gmail.com)**

### **Initial Review – Full Board**

**Re: Approval of Protocol titled: “Stigma and HIV and AIDS treatment seeking behaviour among youths living with HIV in Kampala”**

This is to inform you that, the Makerere University School of Social Sciences Research Ethics Committee (MAKSS REC) granted approval to the above referenced study. The MAKSS REC reviewed the proposal using the full board review on **25<sup>th</sup> January 2018**. This has been done in line with the investigator's subsequent letter addressing comments and suggestions.

Your study protocol number with MAKSS REC is **MAKSS REC 01.18.117**. Please be sure to reference this number in any correspondence with MAKSS REC. Note that, the initial approval date for your proposal by **MAKSS REC was 25<sup>th</sup> January 2018**. This is an annual approval and therefore; approval expires on **24<sup>th</sup> January 2019**. **You should use stamped consent forms and study tools/instruments while executing your field activities at all times.** However, continued approval is conditional upon your compliance with the following requirements.

### **Continued Review**

In order to continue on this study (including data analysis) beyond the expiration date, Makerere University School of Social Sciences (MAKSS REC) must re-approve the protocol after conducting a substantive meaningful, continuing review. This means that you must submit a continuing report Form as a request for continuing review. To avoid a lapse, you should submit the request six (6) to eight (8) weeks before the lapse date. Please use the forms supplied by our office.





**Please also note the following:**

- No other consent form(s), questionnaires and or advertisement documents should be used. The Consent form(s) must be signed by each subject prior to initiation of my protocol procedures. In addition, each research participant should be given a copy of the signed consent form.

**Amendments**

During the approval period, if you propose any changes to the protocol such as its funding source, recruiting materials or consent documents, you must seek Makerere University School of Social Sciences Research and Ethics Committee (MAKSS REC) for approval before implementing it.

Please summarise the proposed change and the rationale for it in a letter to the Makerere University School of Social Sciences Research and Ethics Committee. In addition, submit three (3) copies of an updated version of your original protocol application- one showing all proposed changes in bold or “track changes” and the other without bold or track changes.

**Reporting**

Among other events which must be reported in writing to the Makerere University School of Social Sciences Research and Ethics Committee include:


- i. Suspension or termination of the protocol by you or the grantor.
- ii. Unexpected problems involving risk to participants or others.
- iii. Adverse events, including unanticipated or anticipated but severe physical harm to participants.

Do not hesitate to contact us if you have any questions. Thank you for your cooperation and commitment to the protection of human subjects in research.

The legal requirement in Uganda is that, all research activities must be registered with the National Council for Science and Technology. The forms for this registration can be obtained from their website [www.unsct.go.ug](http://www.unsct.go.ug)

Please contact the Administrator of Makerere University School of Social Sciences Research and Ethics Committee at [makssrec@gmail.com](mailto:makssrec@gmail.com) OR [bijulied@yahoo.co.uk](mailto:bijulied@yahoo.co.uk) or telephone number +256 712 207926 if you counter any problem.

Yours sincerely,



Dr. Stella Neema

Chairperson

Makerere University School of Social Sciences Research and Ethics Committee

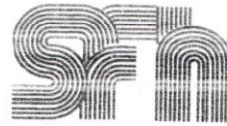


**c.c.: The Executive Secretary, Uganda National Council for Science and Technology**



## Appendix XII: Acceptance Letter

### ST. FRANCIS HOSPITAL NSAMBYA General and Maternity



April 06, 2018

Bro. Anthony Kiwanuka  
Principle Investigator  
Makarere University  
P.O. BOX. 7062

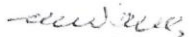
Dear Bro. Anthony

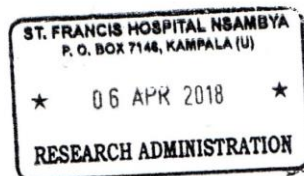
**Re: Letter of Acceptance**

Having received your letter requesting to conduct research on **stigma and HIV and AIDS treatment seeking behavior among youths living with HIV** at our hospital.

I wish to inform you that having submitted all the requirements the IRB had requested I formally accept you for the said research to be conducted in our hospital.

Yours sincerely,

  
Dr. Edward Ddumba  
Medical Director



St. Francis Hospital - Nsambya  
P.O. Box 7146 Kampala - Uganda

Tel: +256-41-267012-3  
Fax: +256-41-267870

E-mail: [nsambya@ucmb.co.ug](mailto:nsambya@ucmb.co.ug), [nsambyahospital@nsambyahospital.or.ug](mailto:nsambyahospital@nsambyahospital.or.ug),  
Website: [www.nsambyahospital.or.ug](http://www.nsambyahospital.or.ug), [info@nsambyahospital.or.ug](mailto:info@nsambyahospital.or.ug)

## APPENDIX XIII: Permission to Conduct Research - Naguru



FOR ANY CORRESPONDENCE ON  
THIS SUBJECT PLEASE QUOTE NO.

CHINA-UGANDA FRIENDSHIP HOSPITAL, NAGURU

P. O. Box 20145,  
Nakawa, Uganda

Tel: Hospital Director: +256-41289741

General Line: +256-414289740



CHINA AID

30<sup>th</sup> April 2018

Mr. Anthony Kiwanuka  
Makerere University  
**KAMPALA**

### PERMISSION TO CONDUCT RESEARCH

Reference is made to your letter dated 25<sup>th</sup> April 2018 requesting this hospital to grant you permission to conduct research, as a requirement for the award of a Degree of Doctor of Philosophy in Social Work. The research topic is **"STIGMA AND HIV AND AIDS TREATMENT SEEKING BEHAVIOR AMONG YOUTHS BETWEEN 18 TO 24 YEARS"**.

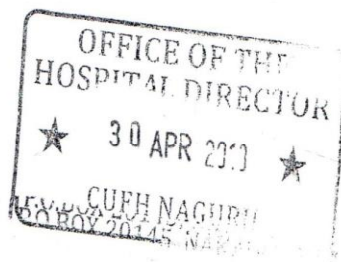
This is to inform you that permission has been granted. You will work with the Head Community Health.

At the end of the study, you must share the research findings with the hospital by providing a copy of the dissertation to the Research Committee and you will be provided with a letter confirming completion of the study.

A handwritten signature in black ink.

Dr. Batiibwe Emmanuel  
**HOSPITAL DIRECTOR**

**Copied to:** Head Community Health



**Figure 8-0-1: Approval to the research**

## Appendix XIV: Approval - Uganda National Council for Science And Technology



### Uganda National Council for Science and Technology

(Established by Act of Parliament of the Republic of Uganda)

Our Ref: SS 4571

10<sup>th</sup> May 2018

Mr. Anthony Kiwanuka  
Makerere University  
Kampala

**Re: Research Approval: Stigma and HIV and AIDS Seeking Behavior among Youth Living with HIV in Kampala**

I am pleased to inform you that on **03/05/2018**, the Uganda National Council for Science and Technology (UNCST) approved the above referenced research project. The Approval of the research project is for the period of **03/05/2018** to **03/05/2019**.

Your research registration number with the UNCST is **SS 4571**. Please, cite this number in all your future correspondences with UNCST in respect of the above research project.

As Principal Investigator of the research project, you are responsible for fulfilling the following requirements of approval:

1. All co-investigators must be kept informed of the status of the research.
2. Changes, amendments, and addenda to the research protocol or the consent form (where applicable) must be submitted to the designated Research Ethics Committee (REC) or Lead Agency for re-review and approval **prior** to the activation of the changes. UNCST must be notified of the approved changes within five working days.
3. For clinical trials, all serious adverse events must be reported promptly to the designated local IRC for review with copies to the National Drug Authority.
4. Unanticipated problems involving risks to research subjects/participants or other must be reported promptly to the UNCST. New information that becomes available which could change the risk/benefit ratio must be submitted promptly for UNCST review.
5. Only approved study procedures are to be implemented. The UNCST may conduct impromptu audits of all study records.
6. An annual progress report and approval letter of continuation from the REC must be submitted electronically to UNCST. Failure to do so may result in termination of the research project.

**Below is a list of documents approved with this application:**

	Document Title	Language	Version	Version Date
1.	Research proposal	English	2.0	December 2017
2.	Informed Consent Forms	English and Luganda	N/A	N/A
3.	Flyer	English	2.0	December 2017
4.	Interview guides	English	2.0	December 2017

Yours sincerely,

Isaac Makhuwa  
For: Executive Secretary  
**UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY**

Copied to: Chair, Makerere University School of Social Sciences, Research Ethics Committee

#### LOCATION/CORRESPONDENCE

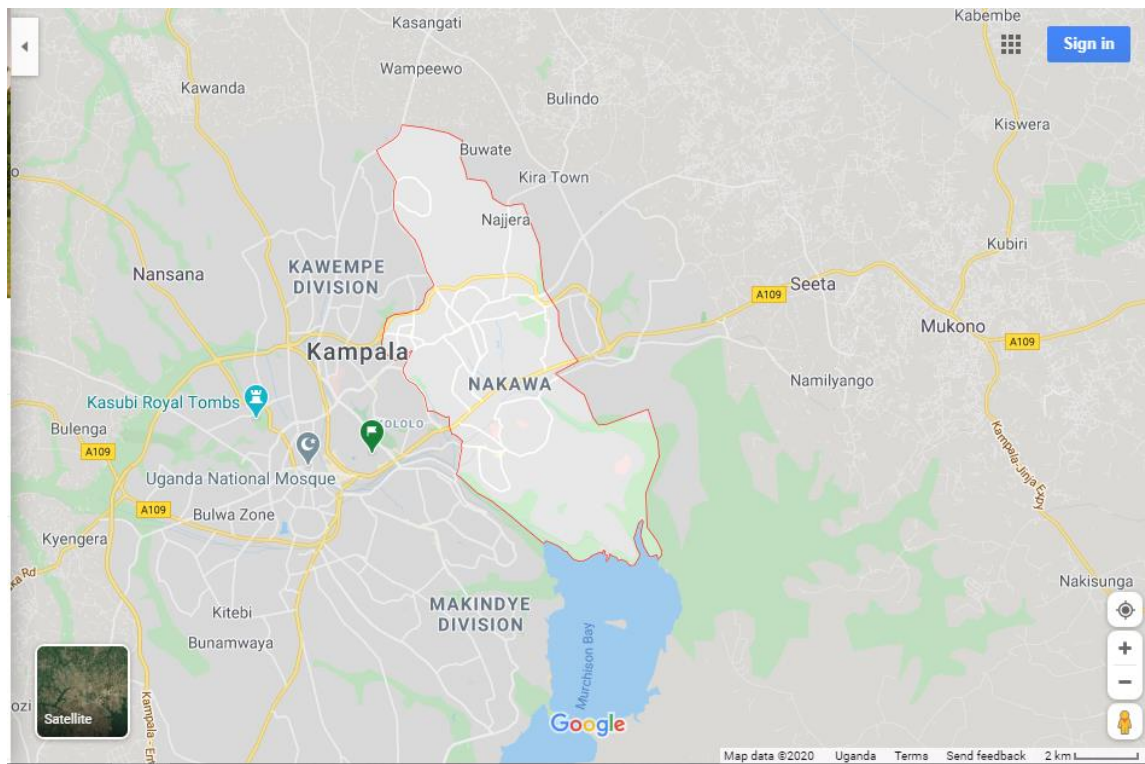
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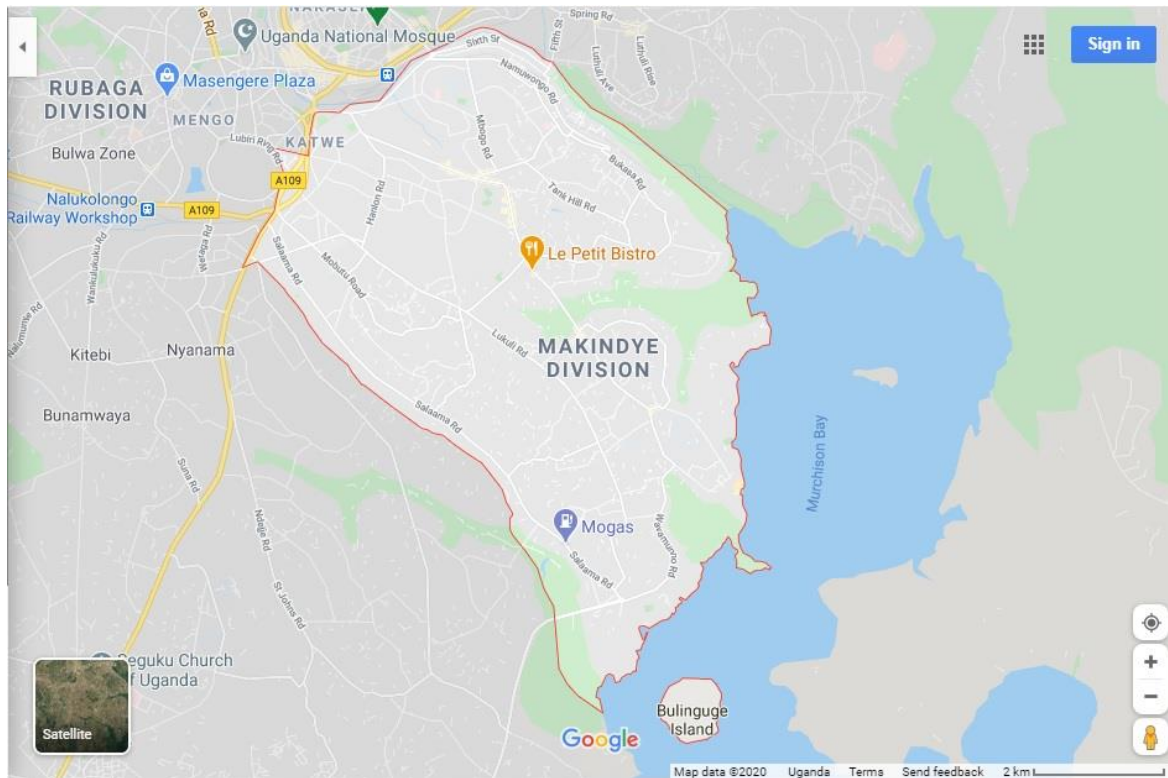
**Figure 8-0-1: Uganda National Council for Science and Technology approval**

## Appendix XV: Maps showing location of the study area



**Figure 8-0-1: Nakawa Division**





**Figure 8-4: Map of Makindye Division**