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## An Exploration of the Lived Experiences of Individuals Living With HIV/AIDS in Rural Uganda

Godfrey Ddungu  
*Walden University*

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# Walden University

College of Social and Behavioral Health

This is to certify that the doctoral dissertation by

Godfrey Ddungu

has been found to be complete and satisfactory in all respects,

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the review committee have been made.

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Walden University

2023

Abstract

An Exploration of the Lived Experiences of Individuals Living With HIV/AIDS in Rural

Uganda

by

Godfrey Ddungu

MA, Cleveland State University, 2014

BA, Makerere University, 2000

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Counselor Education and Supervision

Walden University

May 2023

## Abstract

HIV/AIDS is the most stigmatized health condition globally, yet there are limited studies that have examined the needs of rural Ugandans diagnosed with HIV/AIDS. At a time when Ugandan voices could assist in the development and implementation of prevention and intervention strategies to reduce the spread of the virus, these voices remain unheard and silenced. The purpose of this phenomenological study was to describe the lived experiences of HIV-positive men and women in rural Uganda. A transcendental phenomenological approach provided the framework and design. This research used eight participants who were attending an AIDS health care center in Uganda. In-depth semi structured interviews provided the data for the study; data analysis was consistent with Giorgi's systematic process of reduction. Three major themes emerged from the data: (a) existential threat post HIV/AIDS, (b) resources relative to HIV/AIDS diagnosis, and (c) support from families and friends post HIV diagnosis. The results of this study confirm a need for greater attention and increased mental health support to people living with HIV/AIDS in rural Uganda. The results of this study may help inform training strategies and support services in counselor education programs. This study provided empirical evidence that can be used to advocate for better training of counselors to provide effective services for people living with HIV/AIDS in rural Uganda.

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## Dedication

To my beloved uncles, Fr. Joseph Kakooza -Nynazi and Fr. Emmanuel Katongole, who have provided me unconditional love and support of my work to study the lived experiences of people living with HIV/AIDS in rural Uganda. You both have been a constant source of support and have celebrated every accomplishment. Uncle Joe and Uncle Emma, you are the best, and I cannot thank you enough! In my eyes, we have earned this degree together, and I will always be grateful for your unconditional love, care, and support.

I also dedicate this work to my three children, William Gabriel Ddungu, Gabriella Immaculate Ddungu, and Godfrey Jude Ddungu II. Knowing that you all were watching my process helped motivate a desire to never give up. You all have encouraged me all along the way, and I hope that I will always get the opportunity to encourage you. I have learned that if you just believe in yourself, it is amazing what you can do.

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## Chapter 1: Introduction to the Study

### **Introduction**

While HIV/AIDS is a manageable chronic condition, people diagnosed with HIV/AIDS have a lower life expectancy, are at a higher risk for comorbid diagnoses, and experience a decrease in quality of life (Nasi et al., 2017; Yang et al., 2019). The Centers for Disease Control and Prevention (CDC, 2021b) reported that, in the United States, more than 1 million people aged 13 and older are living with HIV/AIDS. The CDC (2021b) HIV surveillance report on the number of new HIV diagnoses in the United States recorded in 2019 indicated that 13,127 people aged 25 to 35 age group had the highest diagnoses of HIV/AIDS. According to the World Health Organization (WHO, 2021), in 2020, nearly 38 million people were living with HIV globally, 680,000 had died from HIV-related causes, and 1,500,000 had HIV infection. These numbers signify that HIV remains a major public health issue that affects millions of people worldwide. On World AIDS Day 2021, the Director-General of the WHO called on global leaders and citizens to engage in the fight against inequalities that drive AIDS and end the HIV pandemic, especially in developing countries such as Uganda, where people living with HIV are still not receiving essential HIV services (WHO, 2021).

HIV/AIDS representation is disproportionate across demographic and sexual transmission categories (De Jesus & Williams, 2018). Demographically, infections of HIV/AIDS vary by age, sexual orientation, gender, racial and ethnic identity, socioeconomic status, and geographic regions (De Jesus & Williams, 2018). The highest HIV and AIDS incidence rates in the United States occur in the South, while the

Northeastern United States exhibits the highest prevalence of people living with HIV (PLWH; CDC, 2021b). Regional data by the UNAIDS (2019) indicated that out of the global 38 million people living with HIV, Eastern and Southern Africa accounted for 20.7 million people, with 730,000 new cases in the same year. Western and Central Europe and North America accounted for 2.2 million people living with HIV/AIDS (PLWHA) out of the global 38 million PLWHA (UNAIDS, 2019). This disproportionate representation of the infection across demographics points to the inequalities that still exist and drives AIDS in developing countries.

Despite scientific research and innovation that have reduced AIDS-related deaths from 730,000 in 2018 to 690,000 in 2019, the global data show that the numbers of HIV/AIDS infections have been constant, with a staggering number of 1.7 million new HIV infections in years 2018, 2019, and part of 2020 (UNAIDS, 2019). Several studies have indicated that PLWHA in rural and urban areas experience disparate health concerns such as access to care, availability of treatment, quality of care, delayed diagnosis, and stigma (Costelloe et al., 2015; Kalichman et al., 2017). Stigmatization, for instance, contributes to social isolation, avoidance, prejudice, discrimination, and self-devaluation (Kalichman et al., 2017). PLWHA in Uganda continue to experience HIV/AIDS-related stigma. USAID (2020) data on HIV and AIDS in Uganda indicate that PLWHA are less inclined to seek HIV services due to pervasive HIV-related social stigma, conservative attitudes, and stigmatizing legislation. A study on PLWHA found that 40% of PLWHA experienced homophobic abuse, and 44.5% had experienced suicidal thoughts (Avert, 2019). Brown (2021), in her statement during the celebration of Reach Out Mbuya

(ROM) work on HIV/AIDS in Uganda, urged care providers to have critical conversations and interventions to mitigate HIV-related fear and stigma that hinder PLWHA from seeking HIV/AIDS services in Uganda.

In sub-Saharan Africa, persistent HIV-related stigma impedes the success of the global response to HIV/AIDS. However, in recent years, sub-Saharan Africa has had success in expanding access to antiretroviral therapy (ART; Kharsany & Karim, 2016). For example, UNAIDS (2020), in regional coverage of treatment of HIV/AIDS in Eastern and Southern Africa, reported 72% of PLWHA accessing ART. Nonetheless, according to Akatukwasa et al. (2021), low rates of HIV testing among vulnerable populations such as men and young adults and delayed engagement in care among PLWHA persist due to HIV-related stigma. Additionally, research shows that stigmatization for PLWHA can lead to poor mental and physical outcomes and decreases in medication adherence (Kalichman et al., 2017). Although stigma only represents one component of living with HIV, it illustrates the complex relationships that counselors need to understand when addressing the mental and emotional health of clients who have HIV/AIDS. Therefore, this qualitative research study was needed to provide deep insights into the intricacies of the HIV problem and the mental health counseling concerns for Ugandans living with HIV/AIDS in rural Uganda.

## **Background**

Limited research was available related to lived experiences of PLWHA in rural Uganda. However, when I explored the topic with a broader lens, a growing body of literature was available on lived experiences of PLWHA across the continent of Africa

(Madolo, 2020; Omer et al., 2014; Pellowski, 2013; Setlhare et al., 2014). Researchers have explored the diagnosis of HIV and have found that the level of external and internal stigma towards PLWHA is higher in rural areas than in urban areas, which affects all areas of individuals' lives (Akaturkwaswa et al., 2021; Breslow et al., 2020; Li et al., 2018). For instance, PLWHA in Uganda and Kenya deferred marriage, childbearing, distanced from friends and family members, and avoided seeking treatment due to internalized stigma (Akaturkwaswa et al., 2021; Breslow et al., 2020). Additionally, researchers have noted that stigmatization and disease progression of HIV/AIDS have contributed to psycho-emotional disturbances, job losses, poverty, dependence, moving in with relatives, and concerns about strain or disruption of relationships and families (Setlhare et al., 2014).

Researchers have also explored the mental health needs for both PLWHA and service providers involved in rural health services for PLWHA (Modolo, 2020). Researchers have suggested the need for accelerated AIDS treatment and research that contribute to knowledge of an AIDS cure and access to treatment. Developing well-designed research will help PLWHA in rural Uganda learn how to address their concerns. For this study, I coordinated with community health care providers at a health center north of Kampala, Uganda, to collect data. The results of this study could provide opportunities for counselors who want to learn and engage in providing meaningful services to PLWHA. One significant gap found in the literature was the lack of information on lived experiences of PLWHA in rural Uganda. Offering the counseling community scholarly research on lived experiences of PLWHA in rural Uganda could

help broaden perceptions and guide best practices for counselors working with this population.

### **Problem Statement**

AIDS is a life-threatening disease and one of the major global health issues that has resulted in an epidemic of devastating proportions (Kumar et al., 2017). Rural African communities of Uganda face many unique considerations related to the retention and treatment of PLWHA. There are no studies I found that have described the lived experiences of PLWHA in rural Uganda, and yet the research problem is that there are myriad issues of emotional and psychological facing PLWHA. Furthermore, considering the culture of rural Uganda in relation to clinical counseling, there is a dearth of evidence demonstrating mental health help-seeking behaviors and/or lack of knowledge by the counselors themselves. Therefore, a phenomenological design is needed to help gain insight into lived experiences of PLWHA in rural Uganda. The results of this research could illuminate the relevance of stigma in relation to the culture of rural Uganda. Despite mental health counseling services being an important tool in the treatment of HIV or AIDS in many countries in Africa, less than 50% of PLWHA patronize HIV testing and mental health counseling services (HTMC) because of fear of lack of confidentiality and related stigma and discrimination that is related with being HIV positive (Ijeoma et al., 2018; Keine et al., 2015). Understanding the lived experiences of PLWHA in a rural area of Uganda through in-depth interviews will provide insight into the intricacies of the HIV/AIDS problem, counseling concerns of PLWHA, and the

perceived successes of current interventions and prevention strategies in the treatment and prevention of HIV.

Furthermore, the specific problem is that people are suffering due to a lack of literature on mental health counseling services in treating and preventing HIV/AIDS for PLWHA in rural Uganda (Musinguz et al., 2015). Therefore, the people continue to suffer, and counselors do not know how to help in this culture. The social problems in rural areas of Uganda make the problem of the HIV epidemic difficult to eradicate. For instance, many people infected with HIV engage in high-risk behaviors, while others experience stigma and discrimination that stop them from seeking treatment for their HIV-positive status (Camellia, 2018; Musinguz et al., 2015). Epidemiological studies about the survival rate for PLWHA have indicated that those receiving treatment services, including mental health care, have a higher probability of living more than 10 years than those who do not receive treatment (Poorolajal et al., 2016). Furthermore, researchers have reported that PLWHA who have decreased medication adherence experience more significant stigma and poor mental and physical health outcomes (Kalichman et al., 2017). Nonetheless, HIV/AIDS-related stigma and discrimination remain a universal problem that permeates boundaries and operates at multiple levels in society due to fear of death, rejection, and denial (Kumar et al., 2017).

### **Purpose**

The purpose of this qualitative transcendental phenomenological study was to describe the lived experiences of PLWHA in rural Uganda. According to Husserl (1931), transcendental researchers must strictly suspend attitudes, beliefs, and suppositions to

capture the pure experiences of participants. Understanding the pure essence of lived experiences of PLWHA in rural Uganda could provide deep insights into the intricacies of the HIV problem and the mental health counseling concerns for PLWHA.

### **Research Question**

What are the lived experiences of rural Ugandans diagnosed with HIV/AIDS?

### **Subquestion**

How do rural Ugandans experience stigma in relation to their HIV/AIDS diagnosis?

### **Conceptual Framework**

A conceptual framework, as a component of a research design, assists researchers in data analysis and interpretation of research findings (Bloomberg & Volpe, 2008). Phenomenology was the framework for this research study, as the design employs the Husserlian approach that focuses on the conscious knowledge of participants (Moustakas, 1994). Transcendental phenomenology proposes that true understanding of phenomena requires capturing objective occurrences and subjective meaning-making of human experiences (Husserl, 1931; Moustakas, 1994). The Husserlian framework provides a foundation for participants to describe what they perceive, sense, and know (Moustakas, 1994). Because the focus remains on the lived experience of participants, a Husserlian framework allowed me to suspend my opinions by using bracketing (Moustakas, 1994; Shelton & Bridges, 2021). By bracketing, I was able to focus on participants' experiences without any bias and ascertain the true essence of these experiences (Moustakas, 1994). Bracketing my opinions and ideas was critical to the study so that I did not let any

personal experiences bias the study results (Shelton & Bridges, 2021). Bracketing (epoche) makes it possible to arrive at a single, essential, and descriptive presentation of a phenomenon (Groenewald, 2004; Peoples, 2020).

I used Giorgi (1985) as a research expert and a source for descriptive research design. The phenomenological framework involves exploring the lived experience of a shared phenomenon through open-ended interview questions (see Appendix A) so that participants can have the opportunity to express themselves in depth (Peoples, 2020). Husserl developed the phenomenological philosophy in the early 20th century, and Giorgi (1985) later expanded the philosophy into a research design.

### **Nature of the Study**

Based on the problem statement, purpose, and research question, a transcendental descriptive phenomenological approach was the most appropriate for the study. I explored the lived experiences of the phenomenon and bracketed biases to ensure trustworthiness (Neubauer et al., 2019; Shelton & Bridges, 2021). Using a descriptive design, I explored the lived experience of a shared phenomenon through open-ended interview questions so that participants could express themselves in depth.

In concordance with Giorgi (2009), I described the experiences of PLWHA in rural areas of Uganda. Semi structured in-depth interviews offered the best opportunity to explore rich and thick descriptive individual lived experiences of PLWHA that represent the true lived experiences (Giorgi et al., 2017; Husserl, 1931; Peoples, 2020). Understanding lived experiences of PLWHA can assist counselors and other stakeholders working with PLWHA to create a therapeutic alliance that helps address the

psychological and emotional problems of PLWHA in rural areas of Uganda.

Additionally, I used bracketing to reduce prejudgments based on personal experiences, biases, and assumptions brought to the study that could hinder the data accuracy of the study (Giorgi et al., 2017).

### **Definitions of Key Concepts**

The following definitions of terms may assist the reader in understanding the context of each phrase in the study.

*AIDS*: The most advanced stages of HIV infection (WHO, 2021).

*Antiretroviral therapy (ART)*: Treatment with drugs that slows the progress of HIV or other types of retroviruses to multiply in the body and reduces HIV transmission risk (UNAIDS, 2019).

*Counseling professionals*: Refers to professionals who hold a master's degree or higher in mental health and/or rehabilitation counseling and empowering individuals, families, and groups to accomplish mental health, wellness, education, and career goals (American Counseling Association [ACA], 2014).

*HIV*: A condition that affects the human immune system and the body's ability to defend itself against infections (Avert, 2019).

*Diagnosis of HIV*: Refers to persons diagnosed with HIV, regardless of the state of the disease at diagnosis (CDC, 2019d).

*HIV testing and mental health counseling (HTMC)*: Services provided to increase knowledge of HIV status in communities (Ijeoma et al., 2018; Keine et al., 2015).

*People living with HIV/AIDS (PLWHA)*: Individuals who have received an HIV diagnosis as well as those who have been diagnosed with AIDS.

*Bracketing (epoche)*: Refers to researchers' ability to suspend their own preconceptions and not allow their meanings and interpretations or theoretical concepts to enter the unique world of the participant (Groenewald, 2004).

### **Assumptions**

For the purpose of this study, several assumptions guided my approach to data collection. First, I assumed that my background as a Ugandan born and raised in Uganda would increase the likelihood of participants' interest and honest engagement in this project. I also assumed that all participants were supported by the government to receive treatment at the health center with no charge. Another assumption was that all participants engaged in the process would value the nature of this research and would support it through marketing it via their friends in the village who were living with HIV/AIDS. Finally, I assumed that participants who were receiving treatment from the center were coming from the nearby villages, but I learned that many were coming from far distant places to receive treatment.

Regarding the methodology I chose, I assumed that it was possible for researchers to separate themselves from a phenomenon or experience to collect information through a fresh perspective from individuals who had experienced the phenomenon (Giorgi et al., 2017). I also assumed that it was possible to bracket experiences or suspend personal beliefs to help me understand and describe the social and psychological phenomena of participants in the study (Groenewald, 2004; Miller et al., 2018). Finally, I assumed that,

through established methodology, it was possible to review experiential information from participants and analyze it in a way that was descriptive, without inferring meaning or connection from personal experiences.

### **Scope and Delimitations**

A large body of literature points to the issue of HIV and AIDS and PLWHA as an acute problem that needs great attention. Barriers continue to exist and prevent PLWHA from experiencing meaningful social construction of their lives. Data collection and analysis involved in-depth qualitative interviews to explore participants' lived experiences (Creswell & Creswell, 2018). I followed Giorgi et al.'s (2017) specific data collection and analysis procedure to help readers evaluate the scope of transferability to their unique setting. The research participants were located in rural Uganda. I recruited eight adult participants (18 to 45 years old) diagnosed with AIDS. I reached data saturation when there was enough information to replicate the study and no new data, themes, or codes emerged (Fusch & Ness, 2015; Peoples, 2020; Shelton & Bridges, 2021). Research experts have suggested that a larger sample provides the researcher with more accurate study findings, but determining the sample size depends on the qualitative design (Giorgi et al., 2017; Shelton & Bridges, 2021). Furthermore, Vasileiou et al. (2018) pointed out indisputably that saturation is the most known principle for determining the sample size in qualitative research. Additionally, scholars have argued that qualitative research focuses on gaining in-depth information from a small sample of three to 10 participants (Giorgi et al., 2017; Shelton & Bridges, 2021).

Furthermore, I audio recorded, transcribed, and analyzed the interviews to describe the true essence of participants' lived experiences. According to Sutton and Austin (2015), showing empathy and projecting oneself to see and feel whatever circumstance from another person's view is important in qualitative research. Effective qualitative research uses rigorous processes to enhance the findings' credibility, transferability, dependability, and confirmability (Cypress, 2017).

### **Limitations**

The limitations of this study were related to time, participation, representation, and methodology. Although the study met established criteria set forth for a qualitative research design, researchers conducting a qualitative study need to consider how to measure saturation. *Saturation* is a term used in research to indicate that no more new data, themes, or codes in the data collected enhance or change the study's findings (Peoples, 2020). Peoples (2020) argued that while saturation in qualitative research determines the sample size, this may present a problem as to who determines the saturation point or number appropriate to achieve saturation. To ensure that my data collection met the saturation point, I planned to have a small sample of six to 10 participants and explore individual experiences through 90-minute in-depth interviews of participants to increase trustworthiness (Shelton & Bridges, 2021). Additionally, I determined saturation by repetitively seeing or observing the same themes during the data analysis (Peoples, 2020).

Another limitation was my prior assumptions about the phenomenon. Even though researchers use bracketing to block out what they know and feel about a

phenomenon, it is hard to do this (Jackson et al., 2018). To limit this issue and achieve the trustworthiness of my research findings, I ensured that I was intentional in conducting my research and described participants' lived experiences without judgment. Husserl introduced the concept of intentionality, which became one of the cornerstones of phenomenological research, and used it to describe the "life-world experiences or lived experiences" (Giorgi, 2012, p. 132; Giorgi et al., 2017). Husserl's transcendental phenomenological philosophy acknowledges that knowledge is connected to conscious awareness and encourages epoche, or bracketing, to understand the true essence of lived experiences to investigate those lived experiences (Giorgi, 2012). As a concept introduced by Husserl, intentionality allows the researcher to become more aware of phenomena, the lived experiences of participants, and the meaning they attribute to these experiences, which was the purpose of my study (Peoples, 2020).

### **Significance**

This study focused on lived experiences of stigma, discrimination, and barriers to mental health utilization from PLWHA in rural Uganda. These experiences could enable the development of targeted health care practices in improving health outcomes and quality of life for this demographic, including long-term care and positive self-image.

Additionally, findings from this study could foster understanding and create awareness about the lived experience of PLWHA in rural Uganda. Furthermore, the findings may help improve patient outcomes, inform population-specific interventions, enhance quality of life, and give voice to an understudied demographic living with HIV in rural Uganda. I will share the study results with the Uganda Aids Commission (UAC)

and other government-sponsored HIV planning agencies to enhance provider knowledge and develop strategic healthcare interventions to fight HIV/AIDS in Uganda.

### **Summary**

Through this phenomenological research study, I aimed to understand the lived experiences of PLWHA in rural Uganda. My approach involved meeting people where they were at a health center as a safe place, which helped to establish trust. I strived to listen carefully with compassion during the in-depth interview with each participant in the study. Research transparency through informed consent and confidentiality of participants' identities was maintained. Though this study had limitations, I took measures to ensure that the truth of the data was collected and that the findings would benefit the counseling profession and other professionals serving PLWHA. In other words, the in-depth findings generated from this study could demonstrate usefulness in understanding lived experiences of PLWHA in rural Uganda. In addition, unique stories and insights of participants into lived experiences of PLWHA in rural Uganda could contribute to the healing of participants involved in the study and provide counselors and counselor educators a deeper understanding of the experiences of PLWHA in rural communities of Uganda. In Chapter 2, I provide a comprehensive review of the literature associated with this research project and build a case for its value to the profession.

## Chapter 2: Literature Review

### **Introduction**

Rural African communities of Uganda face many unique considerations related to treating and retaining people with PLWHA in counseling centers. PLWHA in rural areas of Uganda experience mental health issues due to minority stress they face associated with being socially categorized (Turan et al., 2017). Although these people need mental health services, often PLWHA are hesitant about seeking counseling services; those who find the courage to seek services also experience stigma and discrimination and conceal their HIV diagnosis (Setlhare et al., 2014). Stigma and discrimination are significant barriers to HIV prevention and engagement in HIV care and treatment. Despite mental health counseling services being an essential tool in the treatment of HIV or AIDS in many countries in Africa, 89% of PLWHA refuse to patronize mental health counseling services because of fear of lack of confidentiality, and 86.7% experience related stigma and discrimination that is associated with being HIV-positive (see Ijeoma et al., 2018). Turan et al. (2017) argued that stigma is a pervasive social process where individuals with HIV in society have a lower social value than those without HIV. Fear and experiences involving HIV-related stigma affect the quality of life and mental health of PLWHA and hinder this group from engaging in HIV care and treatment (see Akatukwasa et al., 2021; Li et al., 2018).

PLWHA in rural areas experience high HIV-related stigma (Akatukwasa et al., 2021). External and internalized stigma has increased among PLWHA in rural Uganda and Kenya (Akatukwasa et al., 2021; Chan et al., 2015). Levels of stigmas toward

PLWHA are higher in rural areas than in urban areas in China (Li et al., 2018).

Furthermore, 18% of PLWHA in rural China experienced external stigma compared to 64% of those experiencing internal stigma (see Li et al., 2018).

The purpose of this phenomenological study was to describe the experiences of PLWHA in rural Uganda. In exploring lived experiences of people living with HIV, I sought to contribute knowledge that mental health counselors can use to understand lived experiences of PLWHA and prepare counselors to work with this population more effectively. Finally, this research will help to inform effective counseling practices and training of counselors in counselor education to provide counseling services to PLWHA in rural areas. The literature review for the study focuses on the needs of PLWHA and training of counselors.

There is limited literature regarding lived experiences of PLWHA in rural Uganda. No specific literature directly addresses HIV lived experiences using the descriptive phenomenology methodology in rural Uganda. In the following sections, I provide an overview of literature search strategies used to gather literature and the conceptual framework for the study before presenting an in-depth review of the literature.

### **Literature Search Strategy**

The literature review for this study focused on peer-reviewed articles published within the last 15 years that are relevant to the major themes of the project. The following databases were employed: Google Scholar, PsycArticles, PsycInfo, Health Science, and Academic Search Complete. The following search terms, in various pairings, were used: *counseling, psychotherapy, HIV, AIDS, acquired human immunodeficiency syndrome,*

*human immunodeficiency virus, Uganda, Africa, Sub-Saharan, rural areas, rural communities, lived experiences, phenomenology, and stigma.*

### **Conceptual Framework**

The Husserlian approach, which focuses on the intentional and conscious knowledge of participants, was the foundation of this study (Cooney, 2012; Moustakas, 1994). Husserl is considered the founder of transcendental phenomenology, a holistic philosophy that he viewed as knowledge coming from the meaning of human experience. What a participant holds in conscious thought is critical to study as it represents knowledge of individuals and the world (Giorgi, 2009). Husserl (1931) said that exploring thoughts requires attention toward detailed descriptions of what participants perceive to appear in the here-and-now. Further, the Husserlian framework provides a foundation for participants to describe what they perceive and sense, as well as knowledge of their immediate awareness and experience (Moustakas, 1994). According to Husserl, all knowledge outside of the individual's immediate awareness is considered inconsequential. Therefore, to fully understand and deduce an experience in a phenomenological study, researchers must suspend their past experiences, thoughts, and ideas (Peoples, 2020; Shelton & Bridges, 2021).

I used the Husserlian framework, including the research technique of bracketing. Bracketing prejudgments, opinions, and ideas ensured the collection of uncontaminated information that reflects the most authentic experience from participants (Giorgi et al., 2017; Husserl, 1931). By employing the bracketing process, I arrived at a single, essential, and descriptive presentation of the phenomenon. Using a Husserlian framework

that focuses on participants' experiences and current awareness, I specifically explored the phenomenon of PLWHA in rural Uganda.

### **Transcendental Phenomenology**

Edmund Husserl is considered the founder of this holistic philosophy, and he viewed knowledge as coming from the meaning of human experience (Groenewald, 2004). From this perspective, intentionality of consciousness is crucial and can be reached by phenomenological researchers moving from participants' descriptions of facts of lived experiences to the essence of the phenomenon (Giorgi, 2009). Husserl (1931) suggested that in order to capture and explicate the essence of lived experiences, participants' detailed descriptions of the phenomenon are critical. These descriptions offer information about the individual's unique perception and knowledge based on the phenomenon experienced in the moment. Consistent with Husserl's perspective, all knowledge outside of the individual's immediate awareness will be insignificant.

### **Descriptive Versus Interpretive Methods**

Scholars who have followed Husserl's theoretical perspective have traditionally taken two roads when considering how to make meaning from research findings (Giorgi, 1997; Heidegger, 1962; Sloan & Bowe, 20014). Some research scholars have preferred a descriptive method, while others have supported the interpretive method to understand the information collected from participants' experiences (Giorgi, 1997: Sloan & Bowe, 2014). Descriptive researchers believe that the foundation for understanding experiential data is analyzing the language used to garner meanings for individuals, with nothing

added or taken away from the description (Giorgi, 2012; Giorgi et al., 2017; Sloan & Bowe, 2014).

Interpretive phenomenological researchers use research questions to ask participants about the meaning of a phenomenon and refrain from bracketing their biases (Giorgi, 2012; Sloan & Bowe, 2014). The interpretive phenomenological researcher aims to understand experiences involving a phenomenon and how study participants make sense of these experiences (Jackson et al., 2018; Peoples, 2020).

In contrast, the goal of descriptive phenomenology is to understand better a phenomenon experienced by participants in their environment (Cooney, 2012). Therefore, when considering the experience of PLWHA in rural Uganda, I used a descriptive method to collect descriptive data on experiences that did not require interpretation, as the data offered inherent meanings for a better understanding of the PLWHA in rural Uganda (Giorgi, 2012; Shelton & Bridges, 2021). Scholars have argued that descriptive phenomenology methodology is one approach that researchers use to get the heart of a phenomenon through the consciousness of participants (Jackson et al., 2018; Peoples, 2020).

### **Literature Review Related to Key Variables and Concepts**

#### **The History of HIV/AIDS**

Scholars have reported that HIV originated in Kinshasa, in the Democratic Republic of Congo, around 1920, when HIV crossed species from chimpanzees to humans (Souquiere et al., 2012). Up to the 1980s, the number of people infected with HIV or who developed AIDS was unknown. HIV, by 1980, had spread to five continents,

including North America, South America, Europe, Africa, and Australia. In 1981, the United States reported the first case of a rare lung infection called *Pneumocystis carinii* pneumonia (PCP) found in five young, previously healthy gay men in Los Angeles (Jaffe, 2018). It has been 40 years since HIV/AIDS was first diagnosed in the United States, yet success in curbing this disease has remained a challenge. Statistical data from 2019 in the UNAIDS Global Report in 2020 on World AIDS Day indicated that more than 38 million people worldwide will be living with HIV/AIDS in 2029. Globally, an estimated 79.3 million people have become infected with HIV. More than 32.7 million people died from AIDS-related illnesses since the start of the epidemic through the end of 2019 (UNAIDS Report, 2020).

### **Definition of HIV/AIDS**

HIV/AIDS refers to human immunodeficiency virus/acquired immune deficiency syndrome. HIV attacks the immune system, which normally protects a person from germs that could make the person sick (Avert, 2019). Once HIV is in a person's system, it lowers the number of healthy immune cells (CD4 cells) or helper T cells that a person has to fight the germs. Thus, the human body cannot fight off viruses, bacteria, and fungi that cause diseases (Avert, 2019). The signs of HIV infections can vary in type and severity from person to person. The CDC has described HIV infection progression in the body if left untreated in three stages. The acute primary infection (first stage) is when the symptoms of HIV feel like having flu. Within 1 to 4 weeks of getting HIV, Stage 2 is the asymptomatic phase, when the individual may feel better. However, the virus is still active in the body and infects new cells and makes copies of itself, which ultimately

damages the immune system. Finally, symptomatic HIV infection is the third stage, when the person's immune system is severely damaged. The person is likely to get serious infections or diseases that the body would otherwise be able to fight off (CDC, 2021a). The symptoms at this stage include weight loss, chronic diarrhea, night sweats, fever, persistent cough, and mouth and skin problems (CDC, 2021b).

### **Treatment of HIV/AIDS**

After more than 40 years of the HIV epidemic, there is still no cure or an effective vaccine; however, there have been significant advances in treating and preventing HIV. For instance, today's treatment of HIV is done through the use of ART drugs to achieve an undetectable viral load, to treat HIV-positive women and their newborn babies to prevent mother-to-child transmission, and to treat HIV-negative people before or after exposure to HIV to prevent HIV infection. All these treatment strategies can reduce the infectivity of HIV-positive people. However, ART in sub-Saharan Africa has had limited success, due partly to PLWHA and their sociocultural preconceptions of western medicine. Adherence to ART in Africa has proven to be a critical issue in the context of inadequate care of PLWHA (Mongo-Delis et al., 2019). In fact, western and central Africa had ART coverage for PLWHA, with only 30% in 2017 (Mongo-Delis et al., 2019).

## **HIV/AIDS and Mental Health**

### **Disorders Commonly Associated With HIV/AIDS Diagnosis**

Mental health professionals do not treat HIV/AIDS. However, mental health professionals do care for the mental and emotional well-being of PLWHA. In 2016,

UNAIDS set the 90-90-90 treatment target, with the aim of ensuring that 90% of PLWHA would be diagnosed, with 90% of them initiating combination antiretroviral therapy (cART) and 90% initiating cART to achieve and sustain viral suppression through adherence to the treatment. Despite good progress, achieving these target goals remains a work in progress. Although these are essential goals, achieving them without addressing the significant mental health and substance use problems among vulnerable people acquiring or living with HIV is a challenge (Remien et al., 2019).

Studies have shown that rates of mental health issues among vulnerable populations whose members acquire HIV/AIDS are high compared to the general population (Remien et al., 2019). Therefore, PLWHA experience higher rates of mental health disorders than the general population. Researchers have reported that mental health disorders are prevalent among PLWHA. An estimated 63% of people living with HIV have a mental health disorder, compared to 31% without HIV/AIDS (Byrd et al., 2020). Research by Remien et al. (2019) showed that people who have HIV/AIDS have a higher rate of experiencing mental health issues and mental health impairment and that people who have mental health issues have an increased risk of acquiring HIV/AIDS. Therefore, the very people whom mental health professionals serve are more likely to contract HIV, and people with HIV are also more likely to have mental health disorders due to their diagnosis.

Remien et al. (2019) reported that PLWHA present double the level of mood disorders than the general population, as one third of them had significant depression and 15.8% had generalized anxiety, compared with only 6.7% and 2.1%, respectively, in the

general population. Furthermore, electronic health records indicated that 41% of PLWHA had a mental health condition compared to 22% of non-HIV infected adults. In Uganda, major depression is more prevalent among PLWHA compared to the general population (Camellia, 2018). However, one study recorded that after 12 months of PLWHA receiving ART treatment, the prevalence of major depression had fallen by approximately 15 points compared to patients who had HIV but did not receive ART (Camellia, 2018). Given this information, mental health professionals can conclude that the problem of mental health issues among PLWHA is double that of the general population.

In medical journal articles, Byrd et al. (2020) and Camellia (2018) documented comorbid issues in PLWHA and argued that many factors contribute to high comorbidity of HIV and mental health conditions. HIV is a significant cause of morbidity and mortality globally. Compared to developed countries where HIV prevalence is declining, sub-Saharan Africa has experienced either a rise or stagnation in rates (Vithalani et al., 2018). Neurological and mental health problems were noted as comorbid issues by Camellia (2018) and Remien et al. (2019). Further, results indicated that the association between mental health and depression, anxiety, and panic attacks could reflect underlying psychological distress and co-concurrence partners (Remien et al., 2019). These results also may highlight a monitoring bias. Individuals living with HIV/AIDS reporting one of the problems can also report another. This shows that these disorders are associated with each other and neurological problems, especially for PLWHA.

## **Treatment and Access**

Screening and treatment of HIV/AIDS are crucial given the strong evidence for the contribution of mental health and behavioral problems to poor HIV health outcomes (Remien et al., 2019). A variety of mental health screenings provide effective clinical care to PLWHA. For instance, the integration of community pharmacists with medical providers has been performed and requires sharing of critical patient information and a collaborative therapy-related action plan (Remien et al., 2019). Remien et al. (2019) showed the importance of connected treatment between medical and therapy. Connection between medical and therapy were found to lead to an improvement in the retention and viral suppression of the virus due to the connection between medical and mental health care services. Therefore, mental health providers need to advocate for collaborative treatment with medical providers of PLWHA.

Furthermore, Remien et al. (2019) noted no differences in the proportions of persons adhering to psychiatric medication and people not adhering to psychiatric medications. Therefore, the connection made the difference irrespective of whether individuals took the medication correctly. Therefore, mental health professionals can firmly conclude that therapy was working, not the medication.

## **Difficult-to-Treat Population Because Members Are Difficult to Identify**

The lived experiences of PLWHA lack representation of HIV/AIDS research. The current research study describes the unique experiences of PLWHA in rural Uganda. The PLWHA know what issues are important to them and their loved ones and what fears and doubts they face in their treatment. PLWHA may be traumatized from the point of their

diagnosis until they die (Pence, 2009). HIV/AIDS diagnosis is considered a life trauma and cause of posttraumatic stress disorder (PTSD) in PLWHA (Pence, 2009). There is evidence that people can grow in positive ways following their trauma because of skills and insights gained through counseling. Remien et al. (2019), in a study with PLWHA in low-income countries, found that mental and behavioral health interventions had a positive effect on the mental health of PLWHA by showing a reduction in depression, anxiety, and overall improvement in quality of their life and psychological well-being. Therefore, it is important for mental health professionals to understand that PTSD in PLWHA could affect adherence to treatment in PLWHA (Ogińska-Bulik & Kraska, 2017).

A study on posttraumatic stress (PTSD) and posttraumatic growth (PTG) in people with HIV showed a high intensity of PTSD symptoms and medium or high intensity of PTG. The study revealed that PLWHA who used an avoidance-focused strategy such as denial, self-blame, and self-distraction to cope with HIV, experienced high PTSD symptoms. In contrast, those who sought emotional support, religion, and acceptance as a coping strategy re-discovered their life's value and hence experienced significant PTG (Ogińska-Bulik & Kraska, 2017).

Many people understand the issues related to the physical side of HIV/AIDS, which is a physical disorder, but many mental health issues are a heavy burden in the lives of PLWHA. For instance, PLWHA experience negative implications such as physical, verbal and neglect abuse, physical violence, and victimization in a relationship where HIV positive partners rape their uninfected partners (Kiwanuka et al., 2021). Also,

trauma is associated with the stigma accompanying HIV/AIDS and the negative sentiments and ill-spoken words used by people in the communities where PLWHA live (Kiwauka et al., 2021). So, as a counseling profession, we want to know how PLWHA cope with physical and mental-related issues like sadness, depression, and anxiety. Additionally, it is crucial that we identify the support systems for PLWHA that supplement the mental health services provided by mental health professionals.

The negative attitude towards PLWHA has contributed to the difficulty of PLWHA accessing treatment and providers accessing the PLWHA. Yaya et al. (2018) noted that the negative attitudes towards PLWHA have resulted in an obstacle in preventing the spread of HIV/AIDS, and PLWHA have failed to get tested and seek treatment. HIV/AIDS stigma and discrimination can have several behavioral consequences, adversely reflecting on the lives of individuals infected with HIV and can be translated into barriers to access to public health services. Despite the rise in the prevalence of stigma and discrimination toward PLWHA and its recognition as a major problem in eradicating HIV epidemic, few countries have prioritized reducing or eliminating stigma and discrimination in their national programs (Kumar et al., 2017). In Uganda, the prevalence of HIV related stigma is 6.2 %, which is higher than other East African countries -Kenya, Sudan, Tanzania, and the Republic of Congo (Kharsany & Karim, 2016). This problem exposes most sexually active people in Uganda to be at a higher risk of acquiring HIV because many do not go for HIV/AIDS testing (Kharsany & Karim, 2016). Therefore, we can conclude that one out of six PLWHA experience stigmatization in Uganda. As a result, PLWHA are difficult to access to start treatment

due to fear of results, acceptance of the diagnosis, prejudice, and discrimination.

Additionally, the high prevalence of stigma is attributed to people not wanting to be seen in clinics because they are being looked at as if they killed someone in their communities (Opio et al., 2019).

### **Differences in HIV/AIDS Experiences in the United States Versus the Rest of the World**

Unlike in other parts of the world (especially Africa), in the United States, the CDC is responsible for collecting, analyzing, and disseminating surveillance data on HIV infection. The CDC's public health partners, in turn, use the data in other health agencies like; health departments, non-profit organizations, and academic institutions to focus prevention efforts, plan services, allocate resources, develop policies that help to detect, monitor, and intervene in HIV infections (CDC, 2017). In his union address in February 2019, President Donald J. Trump announced a plan to end HIV/AIDS epidemic in 10 years (Fauci et al., 2019).

Although one of President Biden's first priorities has been to control the Coronavirus disease epidemic (COVID-19) in the United States, President Biden and his administration have pledged their commitment to end the HIV epidemic in the United States and worldwide. In his statement, the president remarked on the steadfast commitment of his administration to end the HIV epidemic, confront systems and policies that perpetuate entrenched health inequities, and build a healthier world for all people (White House briefing, December 1, 2021).

On World AIDS Day President Biden renewed the United States' decade-long commitment to end the HIV epidemic at home and globally. Additionally, the United States is doubling efforts to confront HIV/AIDS epidemic and achieve equitable access to HIV prevention, care, and treatment for PLWHA, particularly in communities of color, adolescent girls and young women, and the LGBTQ community (White House briefing, December 1, 2021).

Fauci et al. (2019) noted that globally, the United States plays an active role in preventing HIV/AIDS, especially in Africa. The President's Emergency Plan for AIDS Relief (PER FAR) has helped close the gap in HIV treatment and prevention implementation and has addressed disparities between resource-rich and resource-limited nations like Africa (Fauci et al., 2019). Despite the United States' rich resources and the tremendous biomedical and scientific research advances that have contributed to the successful treatment of HIV/AIDS, prevention strategies, and improve the care of PLWHA, the HIV epidemic continues to be a health burden to the United States and the rest of the world (Fauci et al., 2019). For instance, in the United States, although the infection rates of HIV/AIDS and mortality of people with HIV infection is declining, the disparities among minority populations persist, with Latinos and African Americans populations having the highest concentration of HIV/AIDS (De Jesus & Williams, 2018). Many people continue to experience stigma and discrimination associated with having HIV/AIDS both in the United States and the rest of the world. The stigmatization of HIV infection in the United States and globally impedes every step along the HIV continuum of care, particularly care engagement and retention. PLWHA experience HIV stigma

from family members and acts of overt discrimination, resulting in PLWHA disengaging from HIV care, treatment, and support services (Kumar et al., 2017). HIV related stigma, therefore, remains a barrier to HIV care and needs to provide new directions for interventions that focus on understanding the dynamic nature of stigma and the relationship to race/ethnicity.

### **The Experiences of HIV/AIDS in Africa**

#### **The Differences in Experiences of HIV in African Countries**

The HIV/AIDS epidemic remains a significant problem, especially in countries of sub-Saharan Africa like Uganda. For instance, the prevalence of HIV among adults aged 15 and 64 in Uganda was estimated at 6.2% in 2017, representing an estimated 1.3 million PLWHA (Opio et al., 2019; UNAIDS, 2017). Additionally, an estimated 26, 000 Ugandans died of AIDS-related illnesses (Opio et al., 2019; UNAIDS, 2017). The global HIV statistics released by UNAIDS (2020) on World AIDS Day indicated that in 2019 the Eastern and Southern African countries had 20.7 million people living with HIV and 300, 000 AIDS-related deaths. The western and central African countries had 4.9 million people living with HIV and 140,000 related AIDS deaths, and the Middle East and North Africa had 240,000 people living with HIV and 800 related AIDS deaths. Also, there were marked differences in the number of new HIV infections in the different African regions. For instance, Eastern and Southern Africa had 730,000 new infections, western and central Africa had 240,000 new infections, and the Middle East and North Africa had 20,000 new infections. These results suggest a significant need for HIV interventions that

can improve outcomes among PLWHA, especially for countries in Eastern and Southern Africa.

### **The Experience of HIV/AIDS in Different Regions of Uganda**

Uganda is a landlocked country with 41.6 million people, according to the Uganda Bureau of Statistics report 2020 (Uganda Bureau of Statistics, 2020). Uganda lies within the Nile basin and shares its borders with Kenya, South Sudan, the Democratic Republic of Congo, Rwanda, and Tanzania. Four regions comprise Uganda: Northern, Central, Eastern, and Western.

The first cases of HIV/AIDS which became to be referred to locally as 'Slim' in Uganda were reported in 1982 (Vithalani & Villanueva, 2018). Uganda is one of the few countries globally that has managed to reverse its HIV epidemic. Uganda had prevalence rates of 18 -30% in the 1990s, but in the 2000s, these statistics drastically decreased to a prevalence rate of 6.5%. However, the UNAIDS report in 2017 showed a significantly increased prevalence rate of 7.5% in urban and 5.8% in rural areas (UNAIDS report, 2017). Uganda's efforts in combating HIV/AIDS epidemic have focused on prevention, care and treatment, social support and protection, and system strengthening (Uganda Aids Commission, 2021). Despite the national strategic plan by the Uganda AIDS Commission to strengthen social and economic protection of PLWHA, new HIV infections have remained high in various parts of the country, with the central-south, southwest, and central north having the highest percentages. The prevalence of HIV among adults from 15 to 64 years in various regions of Uganda; Kampala 6.9%, Central north 7.6%, central

south 8.1%, southwest 7.9%, East Central 4.5%, Mid-east 5.1%, Mid-west 5.7%, mid-north 7.2%, Northeast 3.7%, and West Nile 3.1% (Uganda Ministry of Health, 2019)

### **Economy and Opportunity in Africa**

In the United States, social service programs by the government supplement income and other basic needs like nutrition, transportation assistance, housing etc. when one faces health problems like HIV/AIDS (Talbert-Slagle et al., 2016). When patients cannot work or support their families due to HIV/AIDS, chronic disease, or physical illness, they may experience psychological problems or mental health issues. These issues may include high blood pressure, anxiety, or depression (Costelloe et al., 2015). All these conditions can impact one's mood, thinking, and behavior. So, in a country like Uganda, where there is no government-provided social support to take care of the family when one is sick, this significantly affects one's mental health, especially for PLWHA.

While scientific research advances have been made led by the United States to develop successful HIV treatment regimens, prevention strategies, and improved care for PLWHA, HIV epidemic remains a public health threat in the United and globally (Fauci et al. 2019). More than 700, 000 people have died due to HIV/AIDS since 1981, and the CDC estimated that 1.1 million people were currently living with the virus, about 15% of whom were not aware of their HIV infection (Fauci et al., 2019). Additionally, Fauci et al. (2019) posited that in Africa, the United States President's Emergency Plan for AIDS Relief (PER FAR) and the Global Fund to Fight AIDS, Tuberculosis, and Malaria have helped reduce the gap in HIV treatment and prevention.

However, this support by the United States has come at a cost. While providing medical treatment to African countries might seem logical, these efforts are ineffective without understanding these countries' cultural perspectives. It should be acknowledged in the development community that despite the benefits of these medical supplies to the health care systems, many people living in Africa are suspicious of western medicine (Nunn, 2020). The provision of access to western medicine is a one-size-fits-all strategy, which is not enough. Western countries must consider the adverse long-term consequences of administering medical services and consider other alternatives that might provide improved outcomes of PLWHA (Nunn, 2020). For instance, the United States needs to collaborate with African mental health professionals to find meaningful interventions that work for Africa's people. The burden of HIV/AIDS is being felt globally and significantly disproportionately affecting underprivileged countries. The National Board of Certified Counselors (NBCC) is already engaged in addressing the need for more excellent mental health support within international communities that lack adequate mental health professionals to provide services (Wagener et al., 2019). The pervasiveness and deleterious consequences of mental health disorders, paired with alarming death rates of African people, call for our profession to prioritize mental health awareness, education, and treatment to combat the barriers facing many people with HIV to seek treatment.

### **Uganda's Efforts to Fight HIV/AIDS**

In 2019, the number of people living with HIV rose from 1.4 million people to 1.5 million people, and an estimated 23,000 Ugandans died of AIDS-related illness

(UNAIDS, 2019). Furthermore, in 2019 Uganda estimated the prevalence of PLWHA between the ages of 15 and 49 at 5.8%, an increase from 2018 at 5.7% (UNAIDS, 2019). New HIV infections were at 53,000 annually, and women are disproportionately affected, with 8.8% of adult women living with HIV compared to 4.3% of men (UNAIDS, 2019)

Despite Uganda's efforts in the fight against HIV/AIDS as evidence of its strategic plans to prevent HIV infections, especially among adolescents and young people, and offer antiretroviral treatment (ART), just under 60% of adults living with HIV on treatment are virally suppressed (Keuroghlian et al. 2021).

PLWHA in Uganda continues to face prejudices and social discrimination. A survey conducted in 2015 by HIV support organizations in partnership with the National forum of people living with HIV/AIDS networks in Uganda (NAFOPHANU) found that internal and external stigma remains high among PLWHA (UNAIDS, 2019). People in several sub-Saharan African countries have reported discrimination, persecution, forced sex, incarceration, and physical violence related to HIV, including government-led initiatives to suppress local advancement through anti-gay policy measures and law enforcement (Keuroghlian et al. 2021).

Legal barriers were documented in Uganda to constrain HIV and AIDS response. For instance, the Anti-Homosexuality Act, initially passed in 2012, is thought to have resulted in increased anti-gay sentiment (UNAIDS, 2019). The Bill criminalized sexual activity between people of the same sex. Additionally, HIV Prevention and Control Act passed in 2014, which gave the mandate to the doctors to disclose the patient's status to the public, also caused concerns to the PLWHA and the international advocates of

PLWHA (UNAIDS, 2019). As a result of these barriers, new HIV infections have continued to rise, and the annual new infections will continue to increase.

### **Cultural Awareness Value in Counseling**

To begin meaningful interactions with African countries, mental health professionals need to reflect on their own different cultural identities and consider how these identities might impact others they contact. In other words, mental health professionals need to be aware of and understand cultural biases and stereotypes that may interfere with helping effectively and learn about the history and culture of a diverse group and new skills (Atkins et al., 2017).

The United States has been engaging with Africa on health care for years (Fauci et al., 2019). Now the mental health component is rising in Africa; the United States and western countries have donated resources to create spaces and places for more connection to globalize effective mental healthcare across Africa (Fauci et al., 2019). If the United States sends resources as aid to fight the HIV crisis in Africa, this must be done in a culturally sensitive way in order to be effective. The United States needs to understand the cultural differences among different parts of Africa. Mental health counseling professionals understand more than ever before the need to look from inside-out of the culture to understand the true story, the workings, and the psychological experiences of a population (Boles, 2017). Our opportunity for global services as mental health professionals has increased, and this is a meaningful calling for our profession. To be effective mental health professionals and other professionals need this inside-out approach as a critical transformation to not only gain cultural proficiency but also to

acknowledge and validate the needs of Africa. When there is no information available about a culture, mental health professionals in the United States cannot serve in that particular culture. Within the tripartite of multicultural counseling competence, counselors gain knowledge defined as understanding the sociopolitical realities of the diverse clients (Atkins et al., 2017). In other words, multicultural awareness allows mental health professionals to develop an increased awareness of their cultural values and others' cultural values, increased intentionality in challenging their perspectives, and engaging in active self-growth to understand the lived experiences of PLWHA (Atkins et al., 2017). This qualitative research study is to help gain knowledge and insights into lived experiences of PLWHA in rural Uganda.

### **Value of Social Justice**

As a counseling profession, we can connect with rural Africa via established programs. For instance, The Bethany Land Institute (BLI) is an established program in rural Uganda for people who have left or are still there but have been affected in some way by HIV/AIDS pandemic in Uganda (Katongole, 2021), This program is looking for ways to create a sustainable living through engaging in sustainable agriculture. There are unique opportunities for the United States professional counselors and counseling programs in the United States of America to get more involved by connecting and partnering with these programs in Africa.

Katongole (2021), in his lecture at Yale Divinity School on his topic "A Different Fulcrum: Doing Theology at Bethany," notes that the purpose of BLI is to provide sustainable living and form leaders engaging in integral ecology for the transformation of

rural communities. His remarks, 'the cry of the earth and the cry of the poor tell us, as professional mental health counselors, about the ecological and social problems facing people in rural areas of Africa. Therefore, counseling mental health professionals need to begin having different ways of thinking and looking at the problem of HIV/AIDS in Africa. Katongole (2021) argues developed countries like the United States that the interaction with Africa should be more than writing prescription recommendations on how to end poverty, donation of medical supplies, and suggestions on making democracy work but this interactive work should be about creating foundational stories that can underwrite new thinking and interventions to offer meaningful ways of caring for PLWHA and people with limited resources in Africa. BLI has created a space where rural and urban people interact with the land, which allows them to maintain their identity and values as Ugandans. A growing body of literature has revealed that contact with nature exposure has long-term benefits on cognitive functioning, emotional well-being, and other dimensions of mental health (Bratman et al., 2019). This integral work at BLI creates practical hope, positive social interactions, a deep sense of connectedness, meaning, and purpose in life among the people in rural Uganda (Bratman et al., 2019). So, there are resources on the ground in Africa to promote life and health, especially PLWHA, and the overall experiences of all people in these areas, not only in urban areas.

### **Summary and Conclusions**

HIV/AIDS is a manageable condition and, with proper treatment and medication management, no longer a death sentence. Despite the medical advancements to treat and prevent HIV transmission, HIV is still a severe health concern worldwide that impacts the

lives of many in rural Uganda (Fauci et al., 2019). Living with HIV/AIDS in rural Uganda includes living with barriers like societal attitudes towards PLWHA, leading to stigma and discrimination. Additionally, many healthcare providers have no training to address stigma and discrimination against PLWHA. There is the existence of frequent discriminatory actions documented against PLWHA among healthcare providers (Kumar et al., 2017). Therefore, counseling professionals have the ethical duty to play the role of social justice advocates for the PLWHA. The American Counseling Association (ACA) code of ethics (2014) emphasizes the core values of the counseling profession as promoting social justice and advocacy concerning human dignity and diversity. After over 40 years of HIV/AIDS epidemic, it is clear that no individual or community is immune to HIV. Underdeveloped countries and marginalized populations or groups are disproportionately affected by HIV/AIDS. They remain at increased risk of experiencing discrimination for HIV and being part of the marginalized group. PLWHA in rural Uganda experience unique circumstances, including stigma and discrimination associated with the disease, which negatively impacts treatment and prevention efforts in rural areas.

Counseling professionals' role in HIV/AIDS treatment and prevention efforts is critical. As a counseling profession, it is paramount to begin having different ways of thinking to help PLWHA cope with the disease in Africa, specifically in rural areas. A study conducted by Mayston et al., (2020) showed that social resources and self-help yield positive therapeutic benefits to PLWHA. Community integration that creates a social environment that is perceived as supportive allows people to come and share

common problems and hence eliminates stigma related to having HIV/AIDS (Mayston et al., 2020).

The research findings of this study will contribute to the current literature by providing deep insights into the intricacies of HIV problems like stigma, discrimination, and barriers to mental health utilization from PLWHA in rural Uganda. Also, the study results may contribute to the development of targeted healthcare practices in improving health outcomes and quality of life for PLWHA, including long-term care and positive self-image. Therefore, this study aims to describe the lived experiences of PLWHA in rural Uganda. In Chapter 3, I describe the methods I used to explore the lived experiences of PLWHA from a transcendental phenomenological approach, including a detailed description of the study's design, rationale, and procedures.

### Chapter 3: Research Method

The purpose of this transcendental phenomenological study was to describe the lived experiences of PLWHA in rural Uganda. There have been research studies on the experiences of PLWHA in rural Africa; however, I found no research regarding lived experiences of PLWHA in rural Uganda using the phenomenological methodology. Much as PLWHA share many similar experiences, understanding the experiences of PLWHA in rural Uganda could provide counselors and other retreatment providers who serve this particular population more insights and information that could contribute to more meaningful and effective services for PLWHA.

An essential step of qualitative research is to carefully underpin it with clear evidence of rigor and ethical soundness to bolster confidence in results (Priest, 2016). In this chapter, I explain the research design, rationale, and procedures to support the study's validity, reliability, and possible generalizability. Additionally, I address my role in the research and potential bias to minimize the possibility of skewed study results due to bias (see Peoples, 2020; Ravitch & Carl, 2016). I describe the methodology for this transcendental phenomenological exploration, including information on participant selection, sampling procedure, and sample size. Last, I explain the data collection and analysis plan and address the trustworthiness and ethical procedures to follow in this study.

#### **Research Design and Rationale**

The research question for this study was as follows: What are the lived experiences of rural Ugandans diagnosed with HIV/AIDS?

This research was further informed by one subquestion: How do rural Ugandans experience stigma in relation to their HIV/AIDS diagnosis?

Because limited research is available to understand the lived experiences of PLWHA in rural Uganda fully, counselors who work with this population have little empirical information to inform how to engage individuals and provide adequate services. To address this gap, I used a phenomenological approach to illuminate the lived experiences of PLWHA in rural Uganda.

### **Identifying the Research Tradition/Research Design and Rationale**

Qualitative and quantitative research are the two primary approaches used to conduct research. I selected a qualitative method of inquiry to explore this topic of my study. While quantitative research requires mathematical processes, researchers have defined qualitative inquiry in various ways (Yilmaz, 2013). Similar to Creswell and Creswell (2018) and Reiners (2012), Yilmaz (2013) defined qualitative inquiry as the "emergent, inductive, interpretive, and naturalistic approach to the study of people, cases, phenomena, social situations and processes in their natural settings in order to reveal in descriptive terms the meanings that people attach to their experiences in the world" (p. 312). Due to this more interpretive approach, qualitative methodology differs from quantitative in that quantitative research is rooted in the constructs of validity, while qualitative research must closely address issues of credibility and trustworthiness (Cope, 2014; Shelton & Bridges, 2021). Describing and understanding lived experiences of PLWHA as participants in the study was the goal of this research instead of quantifying

the connection within these experiences. Therefore, qualitative inquiry offered a structured method to explore the phenomena to address my research questions.

Within the qualitative paradigm, phenomenology as a research design offers various approaches to assist in the exploration and understanding of an experience. There are two main approaches of phenomenology, divided by their different perspectives on what phenomenology is. These two approaches are transcendental/descriptive and hermeneutical/interpretative phenomenology. For example, in using a hermeneutical approach, meaning emerges as participants and researchers weave together and co-construct knowledge (Heidegger, 1962). Transcendental phenomenology is specifically different from a hermeneutical perspective because it involves viewing knowledge as coming from outside participants' immediate awareness as completely inconsequential to the study results (Giorgi, 2012; Peoples, 2020). Instead of “co-constructing” knowledge, in transcendental phenomenology the researcher’s understanding of the phenomenon should be abandoned. Because transcendental phenomenology allowed me to explore information from multiple participants while also requiring me as a researcher to bracket or suspend personal experiences and preconceived ideas and process the data from only the participants’ perspectives, I chose to use transcendental phenomenology as the research design (see Giorgi et al., 2017; Shelton & Bridges, 2021).

Transcendental phenomenology focuses specifically on participants' perceptions as the object of scientific study (Lopez & Willis, 2016; Shelton & Bridges, 2021). Husserl adopted the early beliefs of philosophers Descartes and Kant, who asserted that human perception is the foundation of what is real (Moustakas, 1994). Husserl thus

founded transcendental phenomenology in the early 20th century to present humans' experiences and their awareness of those experiences in a way that allowed researchers to suspend their personal beliefs or interpretations of a phenomenon (Christensen et al., 2017; Peoples, 2020; Reiners, 2012). Acknowledging participants' knowledge as reality, I used the participants' direct description of the experience coming from their intimate engagement with the phenomenon (see Giorgi, 2012).

To elevate participant experiences, I paid particular attention to participants' language as they recalled their experiences to capture rich, thick descriptions that culminated in their truth about the phenomenon (see Christensen et al., 2017; Maxwell, 2013; Peoples, 2020). Additionally, by utilizing Husserl's (1931) descriptive approach to knowledge, I paid attention to the prejudgments or personal perceptions I brought to this study. Acknowledging and setting aside my perceptions required a process of personal reflections and bracketing my preconceived views, assumptions, and biases to allow the uncontaminated natural meaning of the experiences of PLWHA to be captured and understood (see Giorgi, 1997; Peoples, 2020; Shelton & Bridges, 2021). I wanted to gather more than story examples and engage participants in their retrospective understanding of lived experiences of HIV/AIDS, which expanded individual stories into broader meanings. To both capture the lived reality of participants while bracketing my own perceptions, approaching this study from a descriptive perspective provided the best structure (see Christensen et al., 2017; Tufford & Newman, 2012).

Giorgi et al. (2017) described the application of a descriptive phenomenology to psychological processes and explained that, as a philosophical process, the steps are

"descriptive, reduction, and essence" (p. 180). A transcendental phenomenological approach was the most effective method for this study due to the importance of alignment between the research question, purpose of the study, and methodology (Patton, 2015).

Thus, I used this approach and method to structure my study.

### **Role of the Researcher**

Both Patton (2015) and Peoples (2020) argued that one of the most important roles of the researcher in qualitative inquiry is to determine the appropriate structure of the data collection and analytical process such that it is consistent and true to the nature of the research question. Not considering the role of the researcher can compromise the integrity of a study. With this in mind, it was vital for me to offer a transparent view of my interest and relationship to this project to guard against any personal assumptions, beliefs, or biases that might influence the interpretation of meaningful results (Giorgi, 2009; Peoples, 2020).

A researcher conducting a qualitative methodology is considered a tool in the data collection process, and interviewing is a primary method of gaining information in transcendental phenomenology (Englander, 2012; Peoples, 2020). Precise construction of the interview questions can elicit information about the phenomena to encourage participants to explain the experiences in their most basic state (Giorgi et al., 2017). Participants recruited in the study were HIV positive and received HIV-related services at a Health Clinic Center in rural Uganda. I was an active participant during the interview, using semi structured questions to allow knowledge to emerge and change during the data analysis process (see Englander, 2012; Giorgi et al., 2017; Peoples, 2020).

**Positionality**

I was the primary instrument for collecting data, analyzing data, and reporting the findings in this qualitative study (Sloane & Bowe, 2014). With this in mind, I offered a transparent view of my interest and relationship to this project to guard against my assumptions, beliefs, or biases that would have influenced the interpretation of meaningful results (Georgi, 2009). I was born and raised in Uganda, and my knowledge of HIV/AIDS came to my awareness while I was at Naggalama Junior Secondary School. I was interested in exploring lived experiences of PLWHA in rural Uganda because I lost both my parents and my older brother to HIV/AIDS as well as close friends I grew up with within the village.

During junior secondary school, I had little understanding of the disease. However, as I have learned more about HIV/AIDS through higher education, my knowledge and perspective on the HIV/AIDS pandemic have broadened. I have gained much appreciation for research on HIV/AIDS experience, specifically in the developing world. Therefore, exploring lived experiences of PLWHA in rural Uganda could offer new insights and knowledge that would provide an opportunity for mental health counselors to learn and understand the psychological, social, and emotional problems facing the PLWHA in rural areas of Uganda daily. These personal experiences have also contributed to my curiosity and spurred my interest in exploring the lived experiences of PLWHA in rural Uganda. I am aware that these experiences directly inform my unique perspective on this research project.

To fully eliminate my personal bias that might emerge from my experiences of the phenomenon, as a researcher, I employed strategies in this project that would help manage my preknowledge so that new meaning could emerge (Husserl, 1931). Bracketing in descriptive phenomenology is one of the strategies I used to help reduce influence on my personal bias in the study (Finlay, 2014; Giorgi, 2009). Bracketing required that I reflect on personal knowledge gained from outside sources along with intrinsic beliefs, biases, and perspectives that might influence my objectivity during data collection and analysis (Giorgi, 1997; Peoples, 2020). In transcendental phenomenological methodology, researchers use bracketing to ensure that researcher bias does not influence the analysis process (Giorgi et al., 2017; Neubauer et al., 2019; Peoples, 2020). Researcher bias and assumptions are always present in research activities; however, researchers must actively monitor the influence of their research values and passion (Peoples, 2020; Shelton & Bridges 2021; Stahl & King, 2020). Sharing and accepting my responsibility for assumptions and perspectives about the phenomenon; therefore, I sought to prevent or restrict my influences and biases during the collection and analysis of data for the project (Groenewald, 2004).

Additionally, scholars have suggested that a theoretical framework allows the researcher to be imaginative and include all aspects of a study, including the research question, methods, goals, theory, and assumptions a researcher might have about a study (Giorgi & Giorgi, 2003). Research on HIV/AIDS is important because PLWHA experience many psychological and social issues and have an increased risk of developing mental health issues due to social isolation, stigma, and discrimination

(National Institute of Mental Health, 2016). Research studies on HIV/AIDS in sub-Saharan Africa have demonstrated that this region remains the most affected, and HIV-related barriers such as mental health counseling services, stigma, and discrimination continue to affect the quality of life for PLWHA (French et al., 2015)

## **Methodology**

### **Identification of the Participants**

A transcendental phenomenology approach for this study provided the lens through which to illuminate the lived experiences of PLWHA in rural Uganda. Participants in the study were adults and had full-blown AIDS because this study explored the lived experiences of individuals living with HIV/AIDS. Participants were adults actively seeking treatment at a health center in a rural part of Uganda.

### **Sampling Strategy**

Qualitative research focuses on gaining in-depth information from a relatively small sample. In other words, from the sample in a study, a researcher is able to learn in depth about the issues of most importance to the purpose of the study (Patton, 2015). Through in-depth interviews with PLWHA in rural Uganda and the use of bracketing, important information about what individuals experience before and after HIV diagnosis and the meanings attributed to these experiences was uncovered. Furthermore, Husserl, the father of phenomenology, introduced the concept of intentionality to explore and describe lived experiences of the natural world of participants (Giorgi, 2012; Jackson et al., 2018; Peoples, 2020). Phenomenology researchers, therefore, use intentionality to explore lived experiences and provide holistic insight into the participants' life world

(Jackson et al., 2018; Husserl, 1931). Intentionality is about researchers being able to intentionally relate to participants' consciousness of the lived experiences (Husserl, 1931).

To ensure rich descriptions of meaningful experiences, I used purposeful sampling to recruit well-qualified participants for the interviews (Cleary et al., 2014; Peoples, 2020). In qualitative research, a purposeful sampling strategy assists the researcher in selecting participants who will provide the data for analysis (Peoples, 2020). Furthermore, selecting participants who have direct experience with the phenomenon ensures that rich and relevant information is collected (Giorgi, 2009; Peoples, 2020). Additionally, purposeful sample selection ensures that participants' information will answer the questions to be investigated (Peoples, 2020). Because the current study was phenomenological in nature, purposeful sampling ensured that participants selected for the study had similar experiences with the phenomenon to be studied.

### **Recruitment Criteria**

I recruited adult participants between the ages of 18 and 45 who had been diagnosed with AIDS and had contacted the AIDS clinic center in rural Uganda. To begin the process, I introduced myself via email to the director of the health center, who was my contact, and outlined the purpose, criteria, time commitment, confidentiality, and incentives for the participants (Moustakas, 1994) and distributed flyers (see Appendix B) for the study to individuals with HIV/AIDS.

By selecting participants who had similar experiences, I was able to answer the research questions that guided my research study. According to Ravitch and Carl (2016),

although there is no set sample size for a qualitative study, the sample size should be able to provide data saturation. Saturation is a methodological principle that qualitative researchers use in determining the point at which there are no further new data to be collected on the topic to be investigated (Creswell & Creswell, 2018; Peoples, 2020; Shelton & Bridges, 2021). Saturation is a guiding principle of qualitative research and occurs when the researcher observes similar themes repeatedly (Peoples, 2020, 2016). To ensure saturation for my study, I recruited a small sample of eight participants and aimed to explore the individual experiences through 90-minute in-depth interviews of participants. Additionally, I used snowballing to inquire about others interested in participating and sharing their HIV/AIDS lived experiences in the research study (Peoples, 2020; Shelton & Bridges, 2021).

### **Potential Risks, Discomfort, and Anticipated Benefits**

This study had relatively low risks of causing discomfort to participants. However, I was aware that due to the nature of the questions being personal, some participants could feel discomfort about sharing with me due to the sensitive nature of the questions. I disclosed to participants that if they felt any discomfort at any time in the process, they could choose to withdraw from the study without any penalty or consequence. Participants in the study were volunteers, and there were no rewards or incentives for participating in the study. The study results contribute to the body of knowledge about lived experiences of PLWHA in rural Uganda for the counseling profession and other health care providers to this population. This is significant because

counseling education programs and counselors may use this information to provide effective prevention and treatment services for PLWHA.

## **Data Collection and Analysis**

### **Data Collection**

The data for this study came from semi-structured and face-to-face individual interviews with the PLWHA, who shared their lived experiences. During the qualitative data collection process, I was the primary tool (Giorgi, 1997). I scheduled 30 minutes with each participant to read the informed consent, review any important information such as confidentiality, permission to record, and voluntary withdraw from the study (Patton, 2015). The semi-structured interviews lasted for approximately 90 minutes. I used an interview protocol with open-ended questions and followed up with probing questions to help collect the most accurate textual description of what participants were experiencing and the structured descriptions of how they experienced the phenomenon (Moustakas, 1994).

Phenomenological interviewing highlights specific descriptions of lived experiences; it is paramount to gather data through the perspective filter that provides a concrete understanding of the experience (Peoples, 2020). Each interview was pre-planned, a systematic procedure of conducting it, recording, saving, and transcribing the interview data helped ensure that the most accurate representation of information was captured (Giorgi, 1997). The face-to-face interview with participants took place in a private setting at the health center. I did not conduct any interviews for the study in a public or a private home setting.

Each interview began with an introduction, followed by questions, and ended with a systematic wrap-up procedure (Rubin & Rubin, 2012). I used an audio recorder to ensure that concrete verbal descriptions were collected during the interview and did not take notes during the interview to ensure full engagement with participants in exploring their experiences. However, I made brief reflective notes immediately after the interview and while transcribing the audio recording and analyzing the transcript to describe the setting and the relationship with the interviewees (Giorgi, 2009; Korstjens & Moser, 2018; Saldaña, 2016). During the wrap-up, I asked participants to add any additional information they wanted to share to accurately understand and represent the essence of their lived experiences.

### **Data Management**

Research ethics dictates that researchers must protect participants involved in the research study and maintain the confidentiality of any data collected (Peoples, 2020). Researchers, therefore, must take extra precautions by adopting various means to protect the data collected from participants. As a result of the interview, I had the consent forms, the demographic information, which included age, sex, education level (primary, high school or above), marital status (married, unmarried, divorced, or widowed), employment status (employed, unemployed, never worked), audio files, and a word-for-word transcript that I kept secure (Shelton & Bridges, 2021). For the electronic documents, I named participants' files related to the interview with the code to protect the participant's identity (Giorgi, 2009). The only document that was associated with the actual participant names was the original consent that I kept for any follow-up information requested. I

saved the files (consent, audio recordings, and transcript) in a double password-protected Dropbox file. After completing the study, I destroyed all physical copies of the documents and will main the electronic versions for five years or after the publication (Patton, 2015).

### **Data Analysis**

The goal of data analysis for my research study was to interpret data with faithfulness and describe the meaning of an experience through emergent themes (Giorgi, 2009; Reiners, 2012). I adopted the concept of bracketing early on and not merely during the data collection and analysis. Bracketing in phenomenological inquiry is a methodological approach where the researcher deliberately chooses to put aside one's own beliefs about the phenomenon under investigation or what is already known about the subject prior to or throughout the investigation of the phenomenon (Chan et al., 2013; Giorgi et al., 2017; Sundler et al., 2019). I explored my personal experiences as someone born and raised in Uganda and who has lost family members and friends to HIV/AIDS, so I used an audio journal to verbalize my process as I transcribed, coded, and analyzed the interviews. The data analysis process for my research used the transcendental phenomenological approach, which helped me focus on carefully describing what I collected and not inserting interpretations based on my personal experiences of the phenomenon (Giorgi et al., 2017).

To analyze the transcripts, I used Giorgi et al.'s (2017) descriptive phenomenological psychological model, a trusted process developed and used for more than 40 years. Recently, Giorgi and colleagues published a five-step method for effective

descriptive phenomenological data analysis and noted that they added a fifth step to Giorgi's (2009) previously published method to clarify the process. The following are the five steps by Giorgi et al. (2017):

1. To understand the whole experience, read the entire transcript, including how it ends.
2. To remove the natural experience of the phenomena from the analysis process, assume the attitude of phenomenological psychological reduction.
3. Break down the transcript into smaller parts for analysis by separating for meaning. These sections are called meaning units.
4. Transform the meaning units into phenomenologically, psychologically informed descriptions. Several transformations for some meaning units could be required, and other meaning units may not need transformation in this step.
5. Organize the general structure of the experience

During step 4, a psychological attitude and more time with data to go beyond the surface of the information to reach and draw deep meaning (Finlay, 2014; Giorgi, 2009). Husserl's (1931) process of free imagination variation was beneficial in this transformation stage to frame the wording of each unit in a manner that aligns with a more fresh and pure psychological sense of the phenomenon (Giorgi, 2009).

As Giorgi's (2009) method originally described, I hand-coded the data for my study. After each interview, I completed verbatim transcriptions and started initial coding into meaning units as described in Giorgi et al.'s (2017) steps. The meaning units

discovered and transformed highlighted lived experiences of PLWHA in rural Uganda (Giorgi, 2009).

### **Trustworthiness**

The concept of trustworthiness in qualitative research poses the question of whether the research findings can be trusted, transferable, dependable over time, be confirmed by other researchers, and free from the researcher's bias, preferences, and preconceptions (Korstjens & Moser, 2018; Peoples, 2020; Shelton & Bridges, 2021). I established trustworthiness for my study by providing a specific outline of my strategy so that other researchers could review and replicate the process if desired. While some researchers have suggested using member checking or returning transcripts to participants to review and confirm the information, others suggest that this compromises the nature of emergent qualitative work and captures the experiences expressed. For instance, Reiners (2012) noted that Giorgi negates the idea of returning to participants for validation and deems it inappropriate to ask participants or external judges for validation. Since Giorgi et al. (2017) did not include member checking as part of the methodology, I selected not to incorporate it into my research study.

### **Credibility**

The credibility of qualitative research depends on four factors: (a) systematic, in-depth fieldwork, (b) systematic and conscientious analysis of data, (c) credibility of the inquirer, and (d) readers' and users' philosophical belief in the value of qualitative inquiry (Johnson et al., 2020; Patton, 2015). To have credibility for my research proposal, I provided detailed specific methods and procedures to use during the data collection. I

used multiple data sources to support the themes identified from the interviews with participants in the study. Data collection for this study included audio recordings, field notes, and memos that offered reflective notes after the data collection and analysis process. The description of the findings were related to the data of the study, for example, with direct participant quotes and not formulated from my preconceived assumptions about lived experiences of HIV/AIDS (Ravitch & Carl, 2016).

Also, the informed consent that I read to participants before agreeing to participate offered details about confidentiality. I explained to participants that they could withdraw from participating in the study at any time at their own will. By being transparent about the process in the informed consent, participants likely felt comfortable giving me honest responses and accurate accounts of their lived experiences. As a result, this allowed me to reach true and deeper meaning into the phenomenon's reality (Shelton & Bridges, 2021; Sloan & Bowe, 2014).

### **Transferability**

Transferability refers to the ability of the findings to be used by readers of the study (Cope, 2014; Korstjens & Moser, 2018). While qualitative research is designed not to generalize to the broader populations, I suspected the study's findings would be supportive information for practitioners and healthcare agencies to use with PLWHA (Shelton & Bridges, 2021).

### **Dependability**

Dependability, or the consistency of that data analysis by other researchers or with the same type of group, is a controversial measure of trustworthiness in qualitative

research (Cope, 2014; Lemon & Hayes, 2020). Furthermore, Lemon and Hayes (2020) suggested that forced measures (like member checking or expert review) compromise the qualitative process to ensure the same results. However, triangulation is vital to reduce systematic bias. I used current literature to substantiate the dependability of the findings by ensuring that current research supported the findings.

### **Confirmability**

Confirmability refers to the completeness and accuracy of the interpretations and findings derived directly from participants' lived experiences and does not include the researcher's ideas (Johnson et al., 2020; Lemon & Hayes, 2020). I used the data analysis steps that began with the basic meaning units directly from the participants' responses. I provided participants' quotes to support the themes, which provided the reader with a clear connection between the findings and the original data. The transcendental phenomenological method analyzes data and makes meaning directly from participant's language, leaving no room for personal interpretation of lived experiences (Johnson et al., 2020; Shelton & Bridges, 2021).

### **Ethical Procedures**

Ethical considerations are critical to support the safety of all research participants and uphold the integrity of the research study (Remley & Herlihy, 2014). As a licensed and practicing counselor, I adhere to the ACA's (2014) Code of Ethics in counseling, supervision, teaching, and research practice. Therefore, I submit that I followed this code. To ensure that my research study is trusted and abides by ethics and compliance standards, I participated in the Collaborative Institutional Training Initiative (CITI

Program) web-based training course, Doctoral Student Researchers (Certification Number: 46147834). I also completed the application with the Institutional Review Board (IRB) of Walden University to ensure I met all the ethical criteria for the institution's research. The IRB ensured that my research was grounded in quality procedures that adequately protected participants involved in the research (Peoples, 2020; Remley & Herlihy, 2014). I recruited adults between the age of 18 to 45 who had a diagnosis of HIV/AIDS and receiving treatment. Also, I completed a training course on the protection of human research participants.

I provided informed consent to participants both verbally and in writing about the purpose, requirements, benefits, risks, and rights to confidentiality in the study (ACA, 2014). Confidentiality of participants' information was an ongoing process. For instance, I had exclusive access to data files. I assigned each participant in the study and coded identity attached to consent files, audio files, and transcripts associated with their interview and information (ACA, 2014). Additionally, I stored all electronic files in double -password-protected Dropbox. All participants involved in the study and completing the interview process received a US \$10 food voucher for their participation. This gift was not bribe participants to participate in the study; rather, it was used as a token of gratitude for participation, even to those who chose to withdraw from the study.

### **Summary**

In this chapter, I explained the research and design plan I used, and provided sound literature to support my preference. A phenomenological study assisted in understanding lived experiences of PLWHA in a rural part of Uganda. The exploration of

the phenomenon required both interest and a structured procedure. I provided a transparent view of myself as the research instrument to help mitigate bias and assumptions. In this chapter, I also talked about a more comprehensive strategy regarding the methodology and procedures to support the trustworthiness of the study findings. Finally, I explained the plan for selecting participants, conducting interviews, data collection and analysis, and ethical considerations related to my study's specific nature. In the next chapter 4, I describe the study's process, procedures, and findings. Also, I provide detailed descriptions of participants and interview setting.

## Chapter 4: Results

### **Introduction**

The purpose of this transcendental phenomenological study was to further explore and describe the lived experiences of PLWHA in rural Uganda. As such, the following was the research question used: What are the lived experiences of rural Ugandans diagnosed with HIV/AIDS? The study findings may benefit the counseling profession and other professionals serving PLWHA in understanding lived experiences of PLWHA in rural Uganda. In addition, unique stories and insights of participants into lived experiences of PLWHA in rural Uganda could contribute to the healing of participants involved in the study and also provide hope for PLWHA in rural Uganda. Furthermore, the results of the study may benefit counselors and counselor educators by affording deeper understanding of the experiences of PLWHA in rural communities of Uganda.

In this chapter, I provide a detailed description of the process and procedures used in this study, including the setting, demographics of the participants in the study, and my data collection and analysis processes. I offer evidence of trustworthiness by discussing the study's credibility, transferability, dependability, and confirmability. Finally, I discuss the themes that resulted from this research.

### **Settings**

I identified a healthcare center in a rural area north of Kampala, Uganda. After I learned that the healthcare center was already medically compliant and provided treatment for PLWHA, I reached out to the director of the healthcare center via email and asked if she would be willing to distribute or post this research opportunity for the

patients at the healthcare center. The director agreed, and I sent the flyers, which she handed to the patients to recruit participants for the study.

In August 2022, I traveled to Uganda to collect data for the study. I wanted to do this research study in Uganda because I am a native of Uganda, and I speak the same local language (Luganda) that the patients receiving treatment at the healthcare center speak. The healthcare center gave me permission to use a private room in the facility to conduct all eight interviews with the participants. All eight participants felt comfortable doing the interviews in the facility because it was private, convenient, and connected to their medical facility. I used face-to-face and semi structured questions to interview all eight participants. During data collection, I was unaware of any conditions that influenced the participants.

### **Demographics**

Participants provided self-reports of their demographic information at the beginning of each interview. I asked that the participants provide me with basic identifying information about themselves and their children, including age, employment status, marital status, number of years with diagnosis, and education level. I assigned a code to each participant as a pseudonym by using “W” for female and “M” for male with the sequential number of their interview after (e.g., W1, W2, M2, etc.). In the following subsections, I provide an outline of each participant and their demographic information (see Table 1).

**Table 1***Participant Demographic Information*

Participant	Age	Marriage status	Number of children	Employment status	Number of years with diagnosis	Education level
M1	35	Married	2	Unemployed	7	Grade 5
M2	45	Divorced	4	Employed	5	Grade 5
W1	32	Married	8	Unemployed	13	Grade 4
W2	45	Unmarried	3	Unemployed	16	Grade 4
W3	44	Unmarried	7	Unemployed	13	Grade 3
W4	39	Unmarried	5	Unemployed	11	Grade 5
W5	45	Unmarried	6	Unemployed	16	Grade 4
W6	35	Unmarried	7	Employed	1	Grade 5

**M1**

M1 was a 35-year-old married man with two children. He had an 8-year-old son and 5-year-old daughter. He had attended school and completed Primary 7, an equivalent of fifth grade in the United States. He was HIV positive and had known his status for 7 years. He disclosed that he was unmotivated to take the medicine after the diagnosis because he believed he would die and prepared his children for his death. He had lost a great deal of weight, and he did not believe that the treatment would work. However, he was grateful that he had accepted treatment for HIV/AIDS because his health improved. This participant stated,

I am feeling okay right now but at the start I wanted to stop taking medication because I thought I was going to die, but I am glad I did not stop. I started taking

medication when I was about 50 kg but now, I am 75 kgs. If I gave you the picture before I started the treatment, you would also agree with me that I was about to die. I did not have the body and I told my kids that I was going to die. My hands were the size of a chicken leg, and I am grateful to God that I am like this and alive today.

## **M2**

M2 was a 45-year-old divorced male with four children, and reportedly employed. He had three daughters ranging from 12–15 years old, and his son was a 10-year-old. He had attended and completed Primary 7, an equivalent to fifth grade in the United States. He was HIV positive and had known his status for 5 years. M2 disclosed,

For me my thinking about HIV/AIDS was that if I ever find out that I had HIV/AIDS I would kill myself or I go to several pharmacies to buy medication and take them to overdose myself. But I had a friend who encouraged me to go for blood check. I was checked and it was discovered that I had HIV/AIDS or siliimu (Swahiri translation) but what kept me strong and changed the idea I had before of killing myself was the care I received that day from the doctors.

## **W1**

W1 was a 32-year-old female, married with eight children. She had her first child at the age of 16 years, and then her first husband died. She had seven children with her current husband. She had four boys and four girls, and the age range of the children was from 2 years old to 16 years old. She was not employed. She attended school up to

Primary 6, an equivalent to fourth grade in the United States. She was HIV positive and had known her status for 13 years. She stated,

I went to the healthcare center when I was pregnant for a blood check for my first child. The doctors told me that my blood was not okay and the doctors proceeded to counseling me. They revealed to me that I had the virus. I did not know, and I did not expect to be HIV positive. I was shocked and my heart started racing but I got strong in the moment because I was seeing so many people of different caliber who had come at the healthcare center for treatment and who were even looking better than me.

## **W2**

W2 was 45-year-old woman, unmarried with three adult children. Her husband died and she was now raising three grandchildren (three boys aged 11, 10, and 2). She was unemployed. She attended school up to Primary 6, an equivalent to the fourth grade in the United States. She was HIV positive and had known her status for 16 years. W2 mentioned that at the time of her diagnosis she was single but had lost her husband for reasons she did not know. She also indicated that she had a daughter who had HIV/AIDS. It was her daughter who asked her to go the healthcare center for a blood check because W2 was getting sick more often. According to W2,

I was getting sick with malaria frequently and ongoing cough. So, I was not feeling well generally. So, she advised me to come here for blood check. I decided to come, and I came with her and we found a lot of people here. They took my blood, and the results were revealed to me that I had the virus. The

doctors asked me that now that I found out that I have HIV/AIDS what was I going to do? I told them that I am ready to follow any recommendations and start the medication. At the time, I was given cetirizine and Panadol.

### **W3**

W3 was 44-year-old woman, unmarried, who lived with four grandchildren ages 13, 10, 7, and 5 years. She had seven children and 10 grandchildren. She had no employment. She attended school up to Primary 5, equal to third grade in the United States. She was HIV positive and had known her status for 13 years. W3 mentioned that at the time of her diagnosis, she had been separated from her husband and sexually involved with another man whom she disclosed was the one who gave her the virus. She stated,

I was falling sick every time and I was also married with one man at the time. I was in a relationship with a man but I did not know that he had the virus. This man was not the father of my kids. I had separated with the father of my kids and I was living with my kids. So, after some time I got another man who was older than me but I did not know that his wife was sick and on treatment. Some people in the village told me that the man I was involved with had a wife who had HIV/AIDS but I ignored them.

### **W4**

W4 was a 39-year-old unmarried woman. She had five children from two different men and was separated from the two fathers of her children. She lived alone with her children. The ages of the children ranged from 9 years to 16 years. She was

unemployed, and all her children were girls. She attended school up to Primary 7, equal to fifth grade in the United States. She was HIV positive and had known her status for 11 years. W4 disclosed she did know she had the virus until she went for a blood check when she was pregnant. She mentioned that she had been married to a husband who had another wife. The husband married a third wife, whom she suspected to be sick. W4 decided to separate from her husband. She disclosed,

After I separated from my husband, I got another man and got pregnant. I went for a routine pregnancy checkup and at this visit they checked my blood for HIV as well. When the results came, I was told that I had the virus. I was in a big shock and fear. I made every effort to abort the baby because I knew I was going to give birth to a baby who will also have the virus. These efforts to abort failed and with God's mercy I had a healthy baby.

## **W5**

W5 was a 45-year-old woman whose husband walked out on the family. W5 lived alone and had three children (22-year-old son, 19-year-old daughter, and 16-year-old son). She was unemployed. She attended school up to Primary 6, equal to the fourth grade in the United States. She was HIV positive and had known her status for 16 years. W5 was married for 20 years at the time she found out she had the virus. She indicated that she had six children. After her birth of her sixth child, the doctors stopped her from having more children with her permission. She voluntarily requested the doctors for the procedure to be done. When she returned home with her baby, she started getting frequent fevers, prompting her to go for a blood check. She disclosed,

I started getting sick and several times I was taken to small healthcare centers for treatment due to frequent sickness. One time I got a little better and I went to a big hospital for blood check to see what is making me sick all the time. My blood was taken, and the results showed that I had the virus. The man had left our home when the last child was only 3 months old. One day he just got up and left with other women and never returned.

## **W6**

W6 was 35-year-old unmarried woman who lived with two children (a 13-year-old daughter and 2-year-old son). She had seven children altogether. The other five children lived with her sister. The children ranged in age from 2 years old to 19 years old. She was employed. She attended school up to Primary 7, equal to fifth grade in the United States. She was HIV positive and had known her status for 1 year. W6 reported that at the time of her diagnosis, she was pregnant and unmarried. She said,

The first time I did not know. I was pregnant for 6 months and I had gone to the healthcare center for a routine blood check for my pregnancy. When I got at the healthcare center, the doctor asked me to first have blood check and after the results came out, it was found that I had the virus. I feared and was scared for my life and the life of the baby. The doctors encouraged me not fear and that my child was going to be fine as long as I get on medication.

## **Data Collection**

I contacted a healthcare center in rural Uganda and requested the director of the center to distribute a flyer. From his flyer (see Appendix B), I received responses from

eight potential participants, all of whom met the full criteria for inclusion in the study. The criteria outlined that all participants were to be adults between the ages of 18 and 45 years old with a diagnosis of HIV/AIDS and receiving treatment at the healthcare center. After talking with each participant and reviewing the inclusion criteria for the study, I reviewed and verbally read the consent document with each participant. Potential interviewees reviewed the informed consent and were encouraged to ask questions or express concerns about the process. After receiving and reviewing the consent document, the participants provided their signature.

After I had received the participants' signature, they all agreed to a face-to-face meeting. The healthcare center that distributed the flyers offered a private space in the facility, which was a good fit for all of the participants because they preferred meeting face to face. Participants also preferred the healthcare center because it provided safety and security that would prevent any interventions or issues that could interfere with the interview.

Each participant took part in a 90-minute interview. I used a semi structured interview with open-ended questions from the interview guide (Appendix A) and followed up with unstructured probes to ensure that I collected rich, thick data (Giorgi, 2009). I used a handheld audio recording device to capture each participant's language verbatim during the interview. All eight interviews were conducted in Luganda. As a researcher, I am bilingual in English and Luganda. During the translation of the transcripts, I ensured completeness of meaning rather than word-for-word translation. After I completed the Luganda transcripts, I then translated the texts from Luganda into

English. I also used another person who was bilingual in English and Luganda to read through the full transcripts to ensure accuracy of the content of the interview, both the questions posed and the answers provided by the participants. This consultation ensured accuracy and no bias throughout the translation of the Luganda and English transcripts.

During the first interview, the participant struggled with the language related to the question “How do you describe your life?” and was unable to provide a productive answer, likely due to translation issues. I did not use this question in subsequent interviews but asked probing questions to elicit content. For example, I used probing questions such as the following: What can you say about your life now? What changes has your life gone through since you learned that you have the virus? That decision resulted in understanding in the subsequent interviews with the participants. Each interview was concluded with a debriefing, which involved asking if the participant had anything to add to the interview information.

After each interview, I also used memos to record my immediate impressions with both reflective journaling and descriptive information to help reduce researcher bias and assumptions and increase the accuracy of data analysis from the participants in the study (Chan et al., 2013; Christensen et al., 2017; Lemon & Hayes, 2020; Saldaña, 2016). All interviews were completed with no obvious problems related to issues of finding participants.

### **Data Analysis**

Though I started the bracketing process early in my study as I developed the interview questions, I actively participated in bracketing as I transcribed and analyzed the

data I collected (Chan et al., 2013). I had already explored my personal experiences as someone who grew up in Uganda and seeing people dying from HIV/AIDS, so I used an audio journal to verbalize my personal processes as I transcribed, coded, and analyzed the interviews. I used Giorgi et al.'s (2017) data analysis process for transcendental phenomenological studies, which helped me focus on describing what I gathered, rather than inserting interpretations based on my observational experiences in Uganda.

To analyze the transcripts, I adopted Giorgi et al.'s (2017) descriptive phenomenological psychological method of data analysis, as Giorgi and colleagues have spent more than 40 years developing and using sound phenomenological research methods. Specifically, I used the following five steps as described by Giorgi et al. (2017):

1. Read the entire transcript to understand the whole experience, including how it ends.
2. Assume the attitude of phenomenological psychological reduction to remove the natural experience of the phenomena from the analysis process.
3. Break down the transcripts into smaller parts for analysis by separating for meaning. These sections are called meaning units.
4. Transform the meaning units into phenomenologically, psychologically informed descriptions. This step could require several transformations for some meaning units, while other meaning units may only need one.
5. Organize the general structure of the experience.

While part of the endeavor of qualitative analysis is to reduce large amounts of data into understandable codes and themes (Peoples, 2020, p. 32), the researcher also

endeavored to fully represent each participant's meaning in the telling of his/her story. In the first step, I read each interview transcript and all field notes to get a sense of the interview experience as a whole (Giorgi, 2012). After I read the transcript, I made the mental shift to assume the attitude of phenomenological reduction, which places the researcher in a place to experience the written description as phenomena rather than, in this case, events to be interpreted.

In the second step, I took transcripts one at a time and reread them slowly, marking each transition in the meaning of the language. This analytical process corresponds to the process of bracketing or checking of the preconceived ideas and notions about the experience in the transcendental phenomenology (Giorgi et al., 2017). In the third step, I returned to the meaning categories or units and reviewed them carefully, noting which categories had the greatest endorsement by the study participants. These meaning units were organized into themes. The fourth step was reflecting on each of the emerging themes and considering transforming the meaning units into phenomenologically, psychologically informed descriptions (Giorgi et al., 2017). For steps three and four, I read through each transcript and assigned meaning units to the experiences. I then revisited the meaning units to develop them into more phenomenologically, psychologically informed descriptions for easier integration into themes.

In the final step, I organized supporting statements from the participants under each theme and was able to see significant overlap, with consistent overlap in the themes. Each theme contained subthemes, as will be noted later in the chapter. Important to note,

the themes were supported by participant lived experiences. Therefore, it was deemed that data collection had reached saturation point (Fusch & Ness, 2015).

### **Evidence of Trustworthiness**

#### **Credibility**

I used various strategies to establish credibility in the project including attention to triangulation of data sources, informed consent, planning, descriptions, and reflective journaling. I included participants who represented various ages (18 – 45 years of age), and years when the individual received HIV diagnosis. In the study, I endeavored to make participants comfortable to share the most honest and accurate responses by providing an informed consent that outlined confidentiality and the participant's right to leave the study at any time. I carefully followed a structured data collection and analysis process with audio recordings to offer the most accurate language of participant experience and memos to document every detail. Finally, I paid careful attention to bracketing my own biases in this study. I also made notes about descriptions of experience that triggered personal perspectives during the interview process to remain aware of my own bias. Finally, congruent with Giorgi (2012), themes for this study came strictly from the participant language with nothing added or taken away.

#### **Transferability**

The main point of this research was to understand, and not to generalize to others in this type of research. This study focused specifically on the experiences of Ugandans living with HIV/AIDS in a rural area, north of Kampala Uganda. However, bearing in mind the transferability of the study findings, I provided robust information for both male

and women adults living with HIV/AIDS in rural Uganda that could help provide comparative experiences with those living in urban areas and could create a framework for similar comparisons in other parts of the world. Therefore, the findings of this study could likely resonate with similar research studies on people living with HIV/AIDS globally (Patton, 2015).

### **Dependability**

Dependability in qualitative research is controversial, as some experts suggest member checking, expert review, and triangulation as options to ensure the dependability of the themes (Cope, 2014; Gunawan, 2015). Experts disagree on how effective each of these methods are; I did not use member checking because Giorgi et al. (2017) considered it ineffective. I did not use member checking or expert review as a means of trustworthiness checking because I aligned the steps with the process that Giorgi used. As such, I opted for triangulation using current literature to substantiate the themes and thus reinforce the credibility and dependability of the study (Lemon et al., 2020).

### **Confirmability**

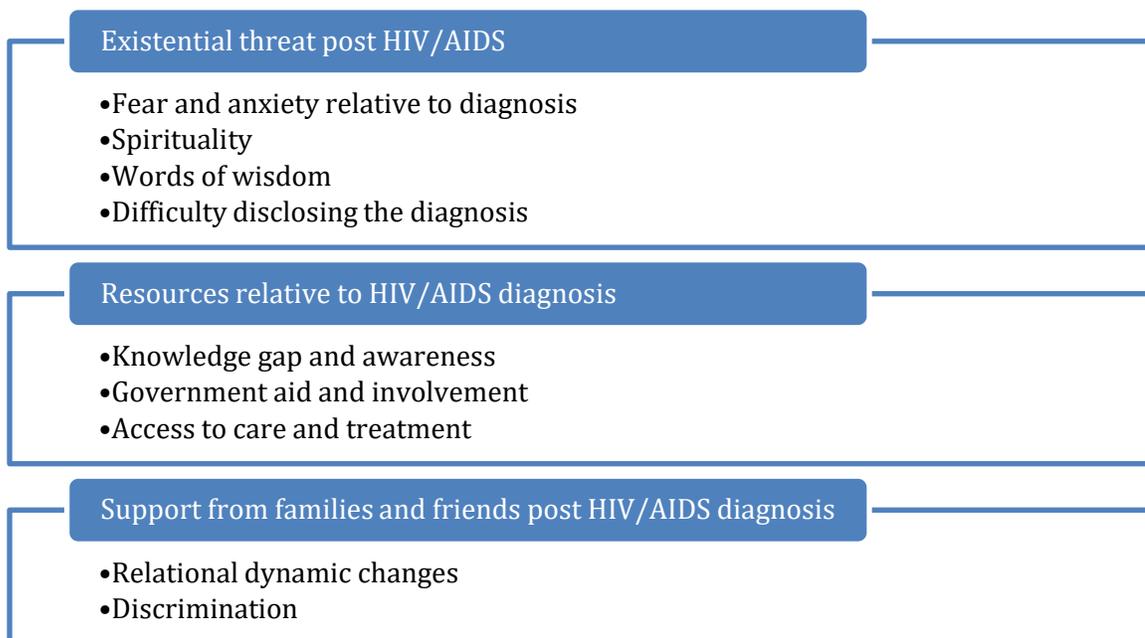
Several strategies helped to bolster confirmability in this research. While I had preconceived ideas that were bracketed, I had no experience of what I was studying, which eliminated the possibility of my direct experiences influencing the analysis. All resulting themes stemmed directly from participant language, leaving no room for personal interpretation. I provided extensively quoted responses to support the themes that connect them back to the original data (Cope, 2014; Finlay, 2014). Finally, when considering the possibility of my own bias, I continually reflected on personal thoughts

and beliefs throughout the data collection and analysis process through journaling, field notes, and memos (Hammarberg et al., 2016; Lemon et al., 2020). Overall, I focused specifically on participant language to ensure the greatest objectivity in study findings.

### **Study Results**

The research question for this study was: What are the lived experiences of rural Ugandans diagnosed with HIV/AIDS? After analyzing the data provided by the participants, three larger themes emerged from the data and they included existential threat post HIV/AIDS, resources relative to HIV/AIDS diagnosis, and support from families and friends post HIV diagnosis. Within each of the themes, sub-themes emerged. Four subthemes were yielded under existential threat post HIV/AIDS and included fear and anxiety relative to diagnosis, spirituality as a source of strength and hope post diagnosis, words of wisdom to providers, government, and the public, and difficulty disclosing the diagnosis, the three subthemes under resources related to HIV/AIDS were knowledge gap and awareness, government aid and involvement, and access to care and treatment, and finally under support from families and friends two subthemes emerged and included relational dynamic changes and discrimination.

See Figure 1 for a visual diagram of the study themes and subthemes highlighted.

**Figure 1***Themes Derived From the Data***Theme 1: Existential Threat Post HIV/AIDS**

All participants shared heightened awareness of death and meaninglessness to life after the diagnosis of HIV/AIDS. Central in the interview, participants discussed the role of spirituality as a meaning-making and coping strategy with HIV/AIDS. All participants identified aspects of their spirituality as a key to coping with the adversity of HIV/AIDS. For the participants, faith played an important role in coping as well as assessing the meaning of their situation of living with HIV/AIDS.

**Subtheme: Spirituality.** All participants had the need to see beyond the diagnosis and hold onto something bigger and still contribute to the family, society, take care of self, help other people, and the need to be able to connect to God was experienced by the majority of the participants. Six out of eight participants I interviewed identified with

God in their situation of living with HIV/AIDS, which was considered a constant source of coping, strength, hope, and coming to terms with the virus. Two did not cite the importance of their relationship with God. For instance, W 1 reported,

not one time, not two times but many times my husband reminds of my status as someone living with the virus even in the presence of our children. My heart hurts but I stand strong and accept my situation as a punishment coming from God.

Another participant uttered a similar narrative as she talked about her desire to contribute and be supportive to her family. W6 said,

God has been good to me, and I not been sick lately. I take my medication daily and I make sure I eat after taking medication. I wake up, go to the gardens morning and evenings to support my children and myself.

Participant (W4) also shared how she experienced psychological distress and symptoms of depression because of her positive HIV diagnosis every day, but her belief in God helped her remain strong for her family. W4 stated,

We pray every day, and my children go to church every Sunday. I tell my children every day that God knows our lives. Many people in our village spend their day without eating due to lack of food but for them God is still providing them what to eat. God has helped me and have not gotten sick or symptoms of the disease yet that would scare my children. For this I am grateful to God.

***Subtheme: Words of Wisdom***

All participants shared their experiences by giving words of wisdom to providers, the government, and the public. Participants desired in amidst of their suffering to be

good to their fellow humans. During the interview, participants shared messages for their fellow Ugandans in rural areas living with HIV/AIDS and those without HIV/AIDS to know about their experiences, and the advice they felt would be helpful to the Government and other Ugandans who are either living with HIV/AIDS or who had not contracted the virus, as they noted that HIV/AIDS is a global pandemic. For instance, M1 stated,

the important thing to do when you have HIV/AIDS is to not engage sexually with other opposite sex individuals. You need to take my medication as directed by the doctors. Many people today live longer into their old age with HIV/AIDS as long as they stay on medication. If you take the medication as directed you will be okay and live longer.

Another participant offered similar statements of words of wisdom to the government. All participants noted how living with HIV/AIDS has caused them to think of themselves as less than and as a result they end up feeling depressed every day. M2 reported,

The government celebrating the AIDS DAY, it should also involve the people living with HIV/AIDS in rural areas. We are not called to participate in this event and yet this could be an opportunity for us to share our stories and have our ideas and experiences be heard. If the government gets involved and supports people with HIV/AIDS in rural areas to access mental health counseling services, this could improve our health and stop being depressed and stressed out all the time in our villages. We need this because we get encouraged.

*Subthemes: Fear and Anxiety Relative to Diagnosis*

Participants also experienced deep anxiety and fear post diagnosis. As such, the following quotes from participants show evidence of fear and anxiety. For instance, W6 reported:

The first time I did not know. I was pregnant for six months and I had gone to the healthcare center for a routine blood check for my pregnancy. When I got at the healthcare center, the doctor asked me to first have blood check and after the results came out, it was found that I had the virus. I feared and was scared for my life and the life of the baby. The doctors encouraged me not fear and that my child was going to be fine as long as I get on medication.

Fear and anxiety by the participants were also revealed through their lack of knowledge about HIV transmission misconceptions. Three out eight participants shared feelings of fear transmitting the disease to their relatives and went as far taking hygiene measures to ensure family safety. W5 stated,

After I got my HIV positive diagnosis, I got sick and told my family not to use the utensils I was using to eat or mix them when washing out of fear of infecting the family members with the virus. Also, I told the family to make sure not to touch or use soft pins found on the floor. I wanted to isolate myself to protect my family.

Other participants also shared their anxiety and fears because they passed on their HIV/AIDS to their child during birth. Participants shared the contention between children and parents related to passing on the HIV virus through childbirth. W2 had six children

and shared that the first five children were born HIV negative, but the sixth child was born HIV positive. Now that the sixth child and the youngest is 16 years old and a teenager, there is a lot of contention in the relationship due to the fact that the HIV virus had passed on to the child even though it was not intentional. More recently, Moyo et al. (2021) reported that pregnant women living with HIV/AIDS in Africa are common, and this has increased the risk of prenatal transmission. Participant W5 stated,

All my children are HIV negative except my last son and the youngest who is HIV positive. His father left us to go with other women when my son was three months old. When my son was about eight years, he started getting sick. School has been a challenge for him and many times I am called at school due to his behaviors. He is 16 years-old now and has started asking me why his siblings were born HIV negative, and he is the only one with the disease. M5 was observed becoming emotional and tears rolled down her face. She continued I tell him that “just take your medication you will be okay” but I do not know if he will ever love me.

***Subtheme: Difficulty Disclosing Diagnosis***

All participants shared both positive and negative experiences of their disclosure of the diagnosis to a family member or someone during the course of illness. Participants discussed their experience of isolation post HIV diagnosis. Participants shared that regardless of the support they had around them from family, friends, partners, or community, they preferred to be in isolation. As a result of social isolation, participants discussed feelings of loneliness which led to them being depressed and increased

irrational thinking. Some participants also shared that despite feeling sick often, they refused to decide to go in for an HIV test until family members or friends got involved and encouraged them to go to a healthcare center for a blood check to know their HIV status. For instance, as evidenced by W2' s statement:

I was getting sick with malaria frequently and on-going cough. I have a daughter who came here first for a blood checkup, and she was found to have HIV/AIDS. So, one time she told me that mother you might want to go to a healthcare center for a blood checkup. This was in 2004 and because of her encouragement, I am so grateful to her. I decided to go in and the results from the blood test showed that I had AIDS and was recommended to start treatment.

Another participant shared that she did not want to disclose her HIV diagnosis because she feared being rejected and accused of giving the virus to her partner. For example, W4 stated,

I never told the man I had about my HIV positive status and he never seen me taking medication the time we were together. I kept the results of my status secret and to my heart.

Participant W6 also shared a similar narrative on the disclosure of her HIV positive status. For instance, she stated,

I have not told him and its hard...I want this person to find out by himself. You know this is hard to tell someone even when you are married. For instance, one partner could be with the virus and there other may not. Therefore, I do not want

to put myself out there, and end up being accused as one who brought the virus.

So, I choose to take my medication in secrecy even if he comes to see the baby.

Another concerning aspect that participants shared regarding disclosing the diagnosis to existing or new relationship was the feedback or advice they received from friends after their disclosure of HIV status. For instance, one participant received misleading feedback from a friend that could have led to her death prematurely. W4 stated:

After I was told that I was HIV positive, I did not take the medication. My friend told me that cooking and drinking using local medicine like marijuana and other local herbs could make the virus kill or weaken the virus. I decided to follow her advice and had three children but on the fourth child I started to get sick and that is when I got on medication.

## **Theme 2: Resources Relative to the HIV/AIDS Diagnosis**

All eight participants discussed that without focused resources and concerted efforts from the government in addressing mental health services, social and economic needs as barriers, PLWHA will continue to experience negative health outcomes at each step in the HIV care continuum. Participants discussed resource content in terms of knowledge gap and awareness, government aid and involvement, and access to care. All participants expressed lack of knowledge of government's support regarding resources needed to deal with their issues like mental health problems, problems accessing care, and barriers related to lack of financial support and transportation.

*Subtheme: Knowledge Gap and Awareness*

Resources show up in many ways. For example, intelligence and education are a resource, but their absence creates barriers. All participants discussed gaps in their knowledge and awareness of what resources were available to support themselves through the crisis. One participant discussed how she got lost in what to do after her diagnosis with HIV/AIDS. She discussed talking with a friend who gave her feedback or advice to use local herbs for her treatment versus going for medical treatment at a health center. W4 stated,

I could have died after my friend gave me misleading information about treatment of HIV/AIDS. After I was told that I was HIV positive, I did not take the medication. My friend told me that cooking and drinking using local medicine like marijuana and other local herbs could make the virus kill or weaken the virus. I decided to follow her advice and had three children but on the fourth child I started to get sick and that is when I got on medication.

The same sentiment regarding a knowledge gap and awareness was also echoed by other participants who lamented that the lack of knowledge and awareness of mental health services in her villages where PWLHA can seek services. For instance, W5 offered,

Here in the villages, we do not have mental health counselors and yet this would have been very helpful for us. We have so many thoughts on our minds and some of these thoughts can lead one to committing suicide. I have heard people with HIV/AIDS in Kampala city have mental health services. I live very far from the

town in the village and I would want to know If we have mental health counselors in our village. The only counselors I know of are the ones here at the center who took my blood.

Another interesting aspect of lack of knowledge and awareness was shared after being asked if client has slept with any other partner post his diagnosis. Participants discussed engaging in sexual encounters with other women post his diagnosis even though he knew this behavior was not appropriate. M2 remarked,

I have slept with multiple women after my diagnosis. At the time I had two eyes before my accident that took away my eye and I would tell women that I love them. I disclosed to them that I have the virus but they could not believe me because I did not show sign of being affected with AIDS. I decided to have sexual relationships knowing that when they find out to have the virus, I will take them to the clinic where I get my treatment.

***Subtheme: Government Aid and Involvement***

Participants talked about the resources they needed, particularly barriers to accessing these resources and barriers to receiving the care they needed. Participants expressed lacking the resources to access treatment or the government that is acting on behalf of this crisis to navigate the HIV/AIDS issues. Participants discussed that government aid and involvement would not only make PLWHA financially independent, but will also allow them to keep their children in school. For instance, W3 said,

Having government aid would make my life much better and easier. For instance, if the government can give us pigs, this can be very helpful because pigs can

reproduce quickly and also easy to sell. For instance, one piglet can cost an equivalent of \$26 dollars. Having such small businesses can help us become independent and be able to support our children to go to school and not drop out.

Similar sentiments by other participants were also made about the governments' lack of aid and involvement to support for people living with HIV/AIDS by failing to fulfil its financial promises. For instance, M1 mentioned,

a couple years ago, the government mentioned that people with HIV/AIDS were going to be supported to start up some small-scale farming, but nothing has been realized. The government had said that whoever had a plot, the individuals were going to be given livestock for farming, but nothing has been seen.

All participants also discussed increased psychological distress and symptoms of depression as a result of experiencing HIV related stigma and a lack of mental health services (Davis et al., 2021). Participants reported that due to a lack of government involvement to aid PLWHA, many people are increasingly getting infected in the villages and are not coming out to be tested or get on treatment. Supporting rural areas to have mental health providers would lead to improvements in the overall well-being of PLWHA in rural Uganda. For instance, M2 stated,

I know receiving mental health services can increase my longevity. Having a mental health counselor coming to my house or in our villages, makes me feel that I am valuable, and my country values my life which in turn encourages me to live happily.

All participants narrated similar messages that the government had not supported PLWHA in rural Uganda and failed to fulfil the promises it has made in past to the PLWHA. For instance, W2 reported,

The government has not supported us. One time we had people from the government coming to our homes and took our pictures promising that they were going to build houses for us but the only people who got housing support were the elderly and not people living with HIV/AIDS. Additionally, the government has supported elderly through goat farming but not people living with HIV/AIDS.

***Subtheme: Access to Care***

All eight participants discussed many different issues that created barriers and their access to care. Some participants described having the availability of care, but others described things that were barriers related to transportation and finances as significant barriers as a result of their positive HIV diagnosis. All participants reported traveling long distances to access HIV treatment and indicated they had no access to motorized transportation. The long travel times needed to reach health-care facilities coupled with high cost of public transportation in rural areas were substantial barriers for the participants to access HIV treatment. For instance, W2 reported,

I am living with my mother. The distance from the healthcare center to my village is about 12 miles. I find it hard to walk this long distance on days when I do not have money for public transportation. Today if I was told that I was not going to be given money for transportation, I would not have come for my treatment. It is a very long distance to walk especially when you not feeling well.

Other participants highlighted financial problems as a barrier to accessing treatment. Participants expressed having difficulty paying the fee that is being charged at the healthcare center for their treatment. Six out of eight participants reported being unemployed. For instance, W4 said,

It is very expensive to get to the healthcare center and yet we still are required to pay a fee of about 12.5 dollars to get medication every month. Also, I did not have money this term to take my daughter back to school because I have to first pay for the last term. She was allowed to seat for her exams last term but did not get the report card until I pay the school fees.

Similarly, another participant shared the same narrative of financial problems. For instance, W6 stated,

The big challenge is getting the money I have to pay at the healthcare center for my treatment. I am required to pay \$12.5 dollars every month and sometimes it is hard to get this money.

Another significant barrier that participants experienced was lack of support from the healthcare providers. Two out of eight participants reported lack of support from care providers. Participants reported negative attitude, delay of service, and rudeness from care providers. For instance, participants discussed that at times patients with extra money in form of bribes were served first irrespective of when they arrived at the healthcare center. For instance, W3 reported,

One time I got here very early at 6:00 am before the doors were opened at 7:00 am. I waited for my medication past 2:00 pm at the health center and then

explained to the doctor that I had not received my medication and yet some people who came before me have received their medication. The doctor responded to me with an attitude and anger and asked me what I wanted him to do. He told me that he did not have many hands to look for my file and that I have to wait.

One participant disclosed that one time she was unable to pay the full two months treatment charge. She paid a half of the money and she was given a one-month treatment dosage instead of a full two months medication supply because she failed to pay her full two months fee. For instance, W1 reported,

One time I had come to the healthcare center with the money for my treatment but because the service delivery was slow, I got hungry for waiting for so long hours and I decided to use some of the money I had brought to pay for monthly fee to buy some food to eat. When I was called to get treatment, the doctor asked me to pay the full fee which was an equivalent of 12.5 dollars but I did not have it. I explained to the doctor that I had used some of the money to buy lunch and requested to pay at my next appointment. The doctor refused to hear my explanation and with anger he told me that he was going to give me medication for only one month instead of the two months I had come for.

After looking at the results of the data findings regarding access to care for PLWHA, the researcher concluded that these barriers significantly prevent access to care in rural Uganda. Even if access to care is available in the villages, if PLWHA do not have transportation or finances, they will not be able to access treatment.

### **Theme 3: Support From Families and Friends Post HIV Diagnosis**

The majority of participants experienced some form of support from their existing friends. Active concern for the well-being of PLWHA is only shown by providing them with support that can improve their quality of life. The need for immediate social and psychological support, therefore, for PLWHA by family, friends, and community is very important.

#### ***Subthemes: Relational Dynamic Changes***

All participants stated that their family relationships were affected either negatively or positively after they shared their HIV status with their family members and friends. When someone has HIV/AIDS in Uganda, relational changes are significant because, in rural Africa, relationships are vital for survival. So, this was a very important change in their lives, and what they were experiencing was a huge change in their lives. Two out of eight participants reported having support of friends who played an active role for their well-being by interacting with them and providing resources they need. W2 described friends who kept her accountable to take her medication when she was unmotivated to do so and just wanted to die. W2 stated narrated:

I have a few friends who have been supportive to me. They have encouraged me that some people live for over 40 years or more if you take your medication and do not stress yourself.

Also, another participant reported a similar narrative of supportive friendship. For instance, W1 mentioned,

I have not lost my friends. They are supportive and I am still talking to them. I call them and they call me to encourage me and this is important to me.

Similarly, M2 shared positive relationship dynamics after the diagnosis. M2 offered, Even though my girlfriend had not told me that she had the virus, she is the one who advised me to go for a blood test. After finding out that I was HIV positive we stayed together because I loved her and we supported each other.

An interesting form of relational support that some of the participants discussed was the messages they received from friends after the diagnosis. One of the participants shared feelings of sadness and guilt but, at the same time, felt supported by her friend.

W5 mentioned,

My friend who used to go out with many men told me after I disclosed my HIV positive status to her that "... I am sorry that you are going to die without enjoying yourself, you married one man and now you have the virus and you are going to be in pain. When she told me that, I felt not supported and I could feel as if my heart had been stabbed.

Throughout other interviews, two out of eight participants shared negative dynamics in spousal relationships, For instance, W1 said,

When my first husband died, I got married to another man and we have seven children together but my husband had been tested several times and he is HIV negative. Because my husband is HIV negative, he treats me as if I am of no use and this makes me feel bad.

A similar negative narrative of spouse relationships was experienced by other participants. For instance, W3 reported,

After I become aware of my HIV positive diagnosis via blood test, I told my husband that I had been healthy and I know he had infected with the virus. He refuted my allegation and accused me that I was the one with the virus and probably I had infected him. I accepted my situation and decided to separate from my husband.

***Subtheme: Discrimination***

Despite the rise in the prevalence of stigma and discrimination toward PLWHA and its recognition as a major problem in eradicating the HIV epidemic, few countries have prioritized reducing or eliminating stigma and discrimination in their national programs (Kumar et al., 2017). Participants highly elevated the issue of discrimination, whether they had directly or indirectly experienced discrimination as a barrier when accessing treatment, acceptance of the diagnosis, and prejudice. For instance, Also, M2 reported,

I was isolated and discriminated by my family member and close friends who started to look at me like I was already dead, something that is not of any value waiting to be put in the dust bin. At first, it was hard for me to come and get treatment because people in the villages talk.

Participants also discussed experiencing discrimination from family members and physically being excluded from participating in family events as a result of positive HIV status. For instance, W2 reported,

My family discriminated me by not even wanting to touch me and be close to me. I was locked in a room and was given food by sliding a plate of food in my room. I could not use the same cup and utensils.

Participants also reported that the majority of people in the villages who are HIV positive are not seeking treatment because of fear of stigma and discrimination post diagnosis. Despite the Uganda government launching campaigns to encourage community outreach with the help of local leaders, participants in the study reported that many people who are HIV positive in villages do not seek out early treatment due to the stigma of being discriminated against. For instance, W4 said,

The people you see here are few. The majority of people who have HIV/AIDS do not come here to get treatment. Many people fear to come to the clinic because they do not want to be seen and judged. Some decided to go to another clinic but many do not go for any treatment. They do not want people to know their status because people will go around talking about them that they are on medication.

In another interview, participant reported discrimination related to employment. Two out of eight participants reported employment discrimination. For instance, M2 reported,

One main challenge I have encountered is employment discrimination. This is so because the people who hire me, once they get to know that I have the virus, they start discriminating me. Many times, I get hired and I finish work, I am not paid. They keep promising me to be paid every other day but they never pay me. My boss knows that I have the virus and I need money to get my treatment but refuses

or delays my payment because he cares more about making his money and not my treatment.

### **Summary**

These common themes of individual experiences of people living with HIV/AIDS offer rich information to help understand the lived experiences of Ugandans living with HIV/AIDS in rural areas. Although participants described many of the same experiences, it is also important to remain aware that every individual experience of people living with HIV/AIDS is unique. The data I collected for this study provided various perspectives of the lived experiences of people living with HIV/AIDS in rural areas of Uganda, and from those experiences emerged three overarching themes which included (1) existential threat post HIV/AIDS diagnosis (2) resources related to HIV/AIDS and (3) support from families and friends post HIV/AIDS diagnosis. Within each of these themes, subthemes also emerged. In the final chapter, I will provide a discussion of my findings, highlight the limitations of the study, make recommendations based on my study and practice, and provide implications for my study.

## Chapter 5: Discussion, Conclusions, and Recommendations

### **Introduction**

The purpose of this qualitative transcendental phenomenological study was to describe the lived experiences of PLWHA in rural Uganda. According to Husserl (1931), transcendental researchers must strictly suspend attitudes, beliefs, and suppositions to capture the pure experiences of participants. Understanding the essence of lived experiences of PLWHA in rural Uganda could provide deep insights into the intricacies of the HIV problem and the mental health counseling concerns for PLWHA. Additionally, the findings of this research could inform counselors, counselor educators, and the government of Uganda's decisions related to HIV/AIDS in rural areas and hence help them begin to design and implement prevention and intervention strategies with successful outcomes to combat the spread of the virus in Uganda. In this chapter, I discuss the findings and the limitations of the study, offer recommendations, and explain the implications for social change of the study.

### **Discussion of the Findings**

The scale of the HIV/AIDS epidemic is difficult to fathom. In 2021, UNAIDS estimated that globally, 650,000 people died of the disease, 37.7 million people were living with HIV/AIDS, and 60% of those living with HIV/AIDS were found in sub-Saharan Africa. Uganda is one of the countries most affected by the AIDS pandemic and has an adult HIV prevalence of over 6.2% (UNAIDS, 2021).

This research study highlights implications for most rural Ugandans because the study results mirrored trends occurring across Uganda. The aim of this research was to

understand and not to generalize to others outside of rural Uganda because the lived experiences for PLWHA are contingent upon the proximal and distal environment (Breslow et al., 2020). Environmental features can include physical structures such as transportation infrastructure, government involvement, and health care systems, as well as social support and interpersonal interactions. The relevant environment can vary within a country and even more widely across countries. For example, lack of transportation may be considered a large barrier in Uganda, while in the United States, it may be a small barrier.

This study focused specifically on the experiences of Ugandans living with HIV/AIDS in rural areas of Uganda. However, bearing in mind the transferability of the study findings, I provided robust information about adults living with HIV/AIDS in rural Uganda that can help in understanding comparative experiences with those living in urban areas and can create a framework for similar comparisons in other parts of the world. Further, the participants in the study represented diverse ages, genders, and years of living with their diagnosis. Therefore, the findings of this study provide supportive information for similar research on people living with HIV/AIDS globally (Patton, 2015; Shelton & Bridges, 2021).

Using a transcendental phenomenological framework, I discussed the findings from the perspective and experience of the participants rather than attempting to interpret the findings (Moustakas, 1994). I used the transcendental phenomenological approach, which suggests that knowledge comes directly from the participant's current perceptions found in their immediate awareness, leaving no room for researcher interpretation

(Giorgi, 2009). Focusing on the experiences of the participants, this study confirmed and extended the findings in the peer-reviewed literature. The research question for this study was the following: What are the lived experiences of rural Ugandans diagnosed with HIV/AIDS? After I analyzed the data provided by the participants, three larger themes emerged from the data. They included existential threat post-HIV/AIDS diagnosis, resources related to HIV/AIDS diagnosis, and support from families and friends post HIV/AIDS diagnosis. Within each of the themes, several subthemes emerged. Existential threat post HIV/AIDS diagnosis generated four subthemes representing the overarching existential threat: (a) fear and anxiety relative to diagnosis; (b) spirituality as a source of strength and hope post HIV diagnosis; (c) words of wisdom to the providers, government, and public; and (d) difficulty disclosing the HIV/AIDS diagnosis. Three subthemes were generated under resources related to HIV/AIDS diagnosis: (a) knowledge gap and awareness, (b) government aid and involvement, and (c) access to care and treatment. Finally, support from family and friends post HIV/AIDS diagnosis as an overarching theme produced two subthemes: (a) relational dynamic changes and (b) discrimination.

### **Theme of Existential Threat Post HIV/AIDS Diagnosis**

All participants shared heightened awareness of death and the meaninglessness of life after the diagnosis of HIV/AIDS. According to Kwong et al. (2019), challenges facing PLWHA include existential conflicts that are experienced as a result of being diagnosed with HIV/AIDS, a significant life event that leads to deep anxiety and a profound sense of threat to one's existence. Central in the interview, participants discussed the role of spirituality as a meaning-making strategy for coping with

HIV/AIDS. Participants in the study identified aspects of their spirituality as key for coping with the adversity of HIV/AIDS, and some even considered HIV/AIDS as a punishment from God (Zainal-Abidin et al., 2022).

For the participants, faith played an important role in coping as well as assessing the meaning of their situation of living with HIV/AIDS. Kwong et al. (2019) noted that challenges facing PLWHA include existential conflicts, which are experienced as a result of being diagnosed with HIV/AIDS. This significant life event leads to deep anxiety and a profound sense of threat to ones' existence.

The results of this study suggested and affirmed previous research that proposed that engaging in spirituality behaviors such as prayer and meditation, participating in religious rituals and rules, and discussing beliefs with others may be effective in protecting against negative consequences of HIV stigma and resulting mental health outcomes (Davis et al., 2021). Thus, one can conclude that there is a need to transcend the diagnosis. The discovery of spiritual meaning for the participants in the study was a unique experience because it influenced the PLWHA to connect and become part of something beyond their control in the face of their illness. Spirituality was fundamentally important for finding meaning and purpose in the world and provided a moral code that guided their behaviors and lives post HIV/AIDS diagnosis (Szaflarski, 2013). Additionally, participants in the study spoke enthusiastically in stating that spirituality helped them to claim acceptance and that they felt they had to live as PLWHA because they realized it was a consequence from God as a result of their previous behavior. Participants in the study used spirituality for psychological coping and well-being as well

as a source of comfort and hope for personal strength (Pinho et al., 2017). Participants felt that God was looking over them and would take on the responsibility, stress, and uncertainty about their health and lives when they died. In other words, despite the adversity, participants in the study looked at God as their supporter and protector who helped them to sustain psychological well-being. For instance, W1 stated,

I have heard several individuals talking about me in passing by them because I have HIV. I choose to ignore them because HIV is not limited to certain people. I know God has a plan for everyone's health. I have HIV, but another person has cancer or blood pressure. So, I just accept what I have from God.

Therefore, participants in this study used spirituality to eliminate their feelings of fear and anxiety due to the stigma attached to their HIV/AIDS diagnosis (Sulung et al., 2019).

### **Theme of Resources Related to HIV/AIDS Diagnosis**

Participants in the study discussed experiencing barriers that prevented them from accessing care. Participants noted that even if access to care was available in rural communities, they did not have transportation or the finances to access care. Many participants believed that without focused resources and concerted efforts by the government to address the problem of mental health services and social and economic barriers, PLWHA in rural Uganda will continue to experience negative health outcomes in HIV care. For instance, W5 offered,

Here in the villages, we do not have mental health counselors, and yet this would have been very helpful for us. We have so many thoughts on our minds, and some of these thoughts can lead one to committing suicide. I have heard people with

HIV/AIDS in city have mental health services. I live very far from the town in the village, and I would want to know if we have mental health counselors in our village. The only counselors I know of are the ones here at the center who took my blood.

Lack of knowledge and awareness of resources, government aid, and involvement and access to care, which includes transportation and financial support, creates barriers for PLWHA that prevent them from being well and living as productive members of society.

Participants cited transportation and distance as the most common barriers to care for PLWHA in rural Uganda. This was not surprising, given the fact that many people who live in rural areas of Uganda must travel to urban or distant places to receive HIV treatment. This means that the health care facilities are not conveniently located and require long travel times. Additionally, PLWHA in rural Africa must rely on sometimes-unreliable forms of transportation, such as public transportation or dependence on others for rides, which are often very costly (Bruser et al., 2021). Participants expressed that because of all these barriers, sometimes it is very difficult for them to travel to appointments for treatment.

Unlike the United States, which has social service programs that can supplement income and other basic needs when one is faced with health problems such as HIV/AIDS, rural Uganda does not have government aid or social service programs for people living with the virus (Kimmel et al., 2016). When a person cannot work and support their family due to HIV/AIDS or other chronic diseases or physical illnesses and has no resources provided by the government, they may develop mental health issues. The information

about the lack of government involvement resonates with the findings of Vithalani et al. (2018), who reported that health experts believe that the government's complacency and stagnant actions may be to blame for the rise of HIV/AIDS.

Furthermore, researchers have mentioned that Africa is the continent most affected by HIV/AIDS and that close to two thirds of new HIV infections can be found in Africa; therefore, governments' involvement in the control and prevention of HIV disease is crucial (Arias-Colmenero et al., 2019). Participants in the study noted experiencing mental health issues and problems such as anxiety and depression and yet had no mental health professionals to talk to them. When PLWHA are in a country such as Uganda where there is not even support or resources from the government to take care of their families when they are sick, this situation significantly affects their mental health (Costelloe et al., 2015).

Additionally, because people with anxiety diagnoses tend to fear rejection by others (Costello et al., 2015), participants shared their fears and anxiety around not knowing what to expect post diagnosis and about telling family and friends. HIV transmission misconceptions and fear of infecting others with the virus have led to isolation of PLWHA and to care providers spending less time providing support to PLWHA (Fauk et al., 2021). The support of care providers for PLWHA has been documented as crucial, but studies have shown that the lack of support from care providers remains an issue. The lack of support of care providers has been seen in the form of compromising behaviors such as fear of contact, delay of services, substandard

services, refusal of care, rudeness of healthcare providers, and breach of confidentiality (Njejimana et al., 2021).

Findings in studies about HIV/AIDS antiretroviral treatment access have also showed that long waiting times for service delivery to people with HIV/AIDS were associated with wastage of earnings (Kosia et al., 2016). Despite the increasing numbers of PLWHA who need antiretroviral treatment coverage, Uganda's fiscal liability to maintain services for all those who are currently receiving treatment for HIV/AIDS is estimated to be as much as 3% of gross domestic product (GDP; (Kakaire et al., 2016). Participants in the study shared difficulties in accessing care due to lack of funding for HIV/AIDS government programs in Uganda, as well as service providers at the health care center asking them to pay a monthly fee to receive treatment. This was further supported by Kakaire et al. (2016), who argued that offering patients sufficient means to assume some of the financial burden for their treatment could help increase coverage and sustain services for those living with HIV/AIDS in Uganda.

The government could aid PLWHA by establishing a goal to create a health care model clinic that focuses on the patient/provider relationship. This relationship would eliminate the feelings of PLWHA being discriminated against by providers and the government. To meet this goal, a "peer buddy system" could be established at the health center in rural areas, which may add to the sense of community for PLWHA. Peer buddies at the health center would reach out to PLWHA to remind them to take their medication, encourage them to seek mental health care from mental health counselors,

and provide general support, hence helping to create a social support network that PLWHA in rural Uganda need (Marahatta et al., 2020).

Additionally, although an additional 12.1 billion pounds in government resources were estimated to be mobilized to fight HIV/AIDS in 2016, 80% of the potential funds were allocated to middle-income countries such as Mexico, Nigeria, Russia, South Africa, Columbia, China, and Argentina, and low-income countries such as Haiti, Uganda, Kenya, and Malawi received only 10% of development assistance funds towards HIV/AIDS care and treatment (Haahenstad et al., 2019). This information suggests that low-income countries such as Uganda have limited capacity to provide much-needed treatment care to PLWHA.

#### **Theme of Support From Families and Friends Post HIV/AIDS Diagnosis**

Due to the fact that PLWHA are likely to face more discrimination and harassment post HIV positive status, the need for support is vital, and, therefore, PLWHA need support in the form of acceptance, affection, respect, and love from friends, family, and community (Kumar et al., 2017). Prodigiously, all eight participants indicated that they had received some level of support when they were first diagnosed with HIV/AIDS. Their support was received from family members, care providers, or friends, or they relied on their faith in God. The participants noted that the way in which they coped with the diagnosis was directly related to the support they had received post HIV/AIDS diagnosis.

All of the participants spoke of significant relationships, which they indicated as either positively or negatively impacting their ability to cope with their initial diagnosis,

as well as ongoing support they continued to receive while living with the virus. For instance, W2 stated,

“I have a few friends who have been supportive to me. They have encouraged me that some people live for over 40 years or more if you take your medication and do not stress yourself.”

Some participants in the study shared how they were negatively impacted to cope with the diagnosis because of the lack of support from their immediate family. For instance, W1 said,

When my first husband died, I got married to another man and we have seven children together but my husband had been tested several times and he is HIV negative. Because my husband is HIV negative, he treats me as if I am of no use and this makes me feel bad.

Additionally, the level of support was also directly tied to their decision of whether or not to disclose their positive status. It should be noted that those who were not able to get support from their immediate families were able to access friends. Overall, however, support was cited as necessary to the participants' ability to cope with the diagnosis of HIV/AIDS.

Evidence from research has shown that individuals living with HIV/AIDS experiencing discrimination and stigma, whether perceived or real, has a profound impact that hinders them from the disclosure of their status a matter of acute concern (French et al., 2015; Kalichman et al., 2017). Although HIV/AIDS disclosure has been considered to

offer a psychological boost and can facilitate better coping strategies for people, disclosure of HIV/AIDS remains critical in Africa (Appiah et al., 2019).

This was also supported by all participants in the study who reported experiencing discrimination and stigma even more impactful due to their living in rural areas of Uganda. In fact, many of the participants reported that living with the virus in rural areas was a unique experience because anonymity could not be ensured if they disclosed their status. As such, participants faced discrimination and stigma from all levels, ranging from family members, friends, people in the village, employers, health care providers, and interestingly the government. This concern is also echoed and supported by research conducted about PLWHA (see Ijeoma et al., 2018). Participants shared that majority of people in the villages who are HIV positive are not seeking treatment because of fear of stigma and discrimination post diagnosis. This finding confirms the findings by other researchers on HIV/AIDS who have posited that the stigma of testing positive has led to an increased number of people from getting tested for HIV even when they suspect of having HIV/AIDS (Vithalani & Villanueva, 2018).

### **Limitations of the Study**

For this transcendental phenomenological study, I recruited eight participants and met data saturation, which met expert suggestions for this type of study (Fusch & Ness, 2015; Patton, 2015). The participants shared the experience of living with HIV/AIDS, but also shared some other experiences. All participants came from rural Uganda, so their experiences of living with HIV/AIDS may be different from PLWHA in urban areas of Uganda. Regional stigma and culture, for example, vary among geographical regions of

Uganda, so the PLWHA in rural areas may experience HIV/AIDS stigma differently than those living in urban areas.

This research revolves around researcher bias. I was born and raised in Uganda, and my knowledge of HIV/AIDS came to my awareness while I was in junior high. I lost not only some of my family members to HIV/AIDS but also close friends from my village whom I grew up and went to school with. My views, therefore, surrounding the experience of PLWHA could have swayed my interpretation of findings and put this study at risk. However, I intentionally used a transcendental phenomenological approach to gather and analyze data that required me to focus specifically on participant language. This approach does not allow any researcher interpretation of findings (Giorgi, 2012). I also took notes and reflected throughout the interview and during the data analysis process to remain keenly aware of personal thoughts and perspectives and limit their influence on the experience. I worked to bracket biases by reporting narratives of experience from PLWHA in rural Uganda in the most uncontaminated manner (Husserl, 1931). Regardless of measures to reduce researcher bias, it can still limit the study in some ways due to the subjective nature of qualitative work (Husserl, 1931).

Another possible limitation of this research was about an adequate sample. Although research participants offered rich, thick descriptions that provided saturation for this study, there was not an extensive variation in age and years with diagnosis among those who responded to the participation invitation. One participant in this study had one year of experience with the HIV/AIDS diagnosis, and the rest of the participants had over five years of experience with the HIV/AIDS diagnosis. It is also important to note that all

participants in the study were over 30 years old. This study would have benefited from greater diversity in age and number of years with the diagnosis among study participants.

Related to the above, all participants were recruited from one health care center. Participants were already in care when data was collected from them about their lived experiences with HIV/AIDS. This could have biased the sample or biased the participants' actual reporting of their specific lived experiences. For instance, it could be possible that the most significant barriers for PLWHA in rural Uganda are not yet known because those barriers prohibit individuals from ever seeking care. However, consistency across the participants amongst the PLWHA, led me to believe that at least the most significant experiences for PLWHA were identified. Addressing this limitation, future studies should include collection of data from both individuals on treatment and those that are not on treatment and are HIV positive to allow a more multilevel analysis of the lived experiences of PLWHA in rural Uganda.

Another limitation was the researcher had to have the research questions translated into Luganda as a local language that all participants spoke. Even though I shared and spoke Luganda as a common language with all the participants, translation of the participant's experiences could change the themes that emerge from the data analysis and may not reflect what the participants actually said.

Nevertheless, even with the limitations noted, my findings illuminated highly on the need for support, the barriers that prevent PLWHA access to care, and HIV/AIDS experience being seen as an existential crisis in rural Uganda. According to Kwong et al. (2019) challenges facing PLWHA include existential conflicts which are experienced as a

result of being diagnosed with HIV/AIDS, a significant life event that leads to deep anxiety and a profound sense of threat to one's existence. All these findings provide deep insights into the intricacies of the HIV/AIDS problem and the mental health counseling concerns for PLWHA in rural Uganda.

### **Recommendations for Further Research**

There are many opportunities for further research concerning PLWHA in rural Uganda. Findings from the study have shown that there are many unique considerations related to support, barriers, and existential crisis that are influencing and affecting the quality of life of PLWHA in rural Uganda. From this study, mental health counselors and other providers can begin to understand the difficulties and the needs of PLWHA in rural Uganda. Since the needs of PLWHA are multifaceted (Kumar et al., 2017) and individuals with other serious mental illnesses use an array of support services to improve their lives (Kumar et al., 2017; Pratt et al., 2014), a follow up study that focuses on the lived experiences of PLWHA in rural Uganda will provide a different perspective. With additional insight and understanding of different perspectives, counselors and counselor educators may have more knowledge of the needs of PLWHA and, hence increase counselors' understanding of how to best intervene and support this population.

Additionally, the results of the study illuminated the values and the impact of support through relational experiences. A prominent concern and difficulty expressed by all participants in the study was the desperate need for family, social, and community support because of the specific needs of rural Uganda where relationships are considered sources of meaning. Relationships are significant in rural Uganda, and they are vital for

survival. Unfortunately, an HIV diagnosis alters the types of needs for PLWHA as human beings. Wissing et al. (2020) noted that relationships from an African context are seen through the lens of interconnectedness, interdependence, sense of solidarity, and a feeling of belonging. Social connectedness, therefore, lies at the heart of care and support of African people, especially those living with HIV/AIDS. Therefore, counselors looking at the findings of this study may gain a deeper understanding of the struggles that PLWHA experience and hence help work with PLWHA to deal the internal distress, create healthy support systems and relationships, and help them learn how to find resources themselves.

### **Implications for Social Change**

Professional counselors are acutely aware more than ever before of the impact of social change factors on the person's well-being. When mental health and physical health are connected, people do better with HIV/AIDS. Also, not only do rural Africa and specific countries like Uganda, which do not have good medical care and do not have the therapeutic care to the standard like that in United States, rural Africa continues to experience social problems like unemployment, poverty, and lower socioeconomic status. As a counseling professional, this is the direction, we need to begin meaningful conversations to strengthen positive responses to HIV/AIDS in resource-poor countries. This research has shown that health and social issues continue to be critical factors facing PLWHA.

As professional counselors, we do not understand what it is like to have HIV/AIDS in rural Uganda. If we are going to connect the models of healthcare, we have

to understand what it is like to have HIV/AIDS. This is why we have to do qualitative research to understand the lived experiences of PLWHA.

So, if we are going to do well for all people, especially those living with HIV/AIDS, we must understand their experiences and what works for them. We know connecting these levels of care, which involves the people who are serving people in rural Uganda will help in the treatment of PLWHA. By connecting with these levels of care, we can then be able to know what is available, what is missing, and then do more research.

As a counseling profession, there is something we can do and how we can connect with rural Africa. For example, The Bethany Land Institute (BLI) is an excellent example that has established programs in rural Uganda for people who have been impacted either by the pandemic of HIV/AIDS or other illnesses. Many of the people at the BLI have lost family relatives due to the HIV/AIDS pandemic in Uganda, and some are looking for ways to create a sustainable living through engaging in sustainable agriculture. There are unique opportunities for professional counselors and counseling programs in the US to get more involved by connecting and partnering with these types of programs in Uganda and Africa. Katongole (October, 2021), in his lecture at Yale Divinity School on his topic “A Different Fulcrum: Doing Theology at Bethany” noted that the purpose of BLI is to provide sustainable living and also form leaders by engaging in integral ecology for the transformation of rural communities. His remarks ‘the cry of earth and cry of the poor’ tells us about the ecological problems and the social problems that are facing people in rural areas of Africa. As a counseling profession, we must be

willing to look beyond our own immediate surroundings and communities and give attention to those that are impacted by HIV/AIDS in the under resourced countries. This study is an invitation for the counseling profession to begin having different ways of thinking and looking at the problem of HIV/AIDS as a global issue.

Katongole (2021) argues that the interaction of western developed countries with Africa should be more than writing prescription recommendations on how to end poverty, eradicate HIV/AIDS, donating medical supplies, and make democracy work which are important as they are, but what we need are new stories, foundational stories, that can underwrite new thinking and interventions within which meaningful ways of caring for PLWHA can be realized in Africa. BLI has created a space where rural as well as urban people interact with the land, which allows them to maintain their identity and values. This integral work at BLI provides practical hope, and a deep sense of connectedness among the people with and without HIV/AIDS in rural Uganda, and also gives them the inner strength to carry on their lives.

### **Conclusion**

There is an urgent need to intervene in the challenges facing PLWHA in rural Uganda. It is essential that the government of Uganda as well as counselors and educators recognize and respond to the support needs of PLWAHA not only in rural Uganda but also in rural Africa. The United States has been engaging with Africa for years in health care, and now the mental health component is increasing, the need to create spaces in and out of Africa that place importance on more connection to globalize effective mental healthcare across the country is crucial. If we are going to send people to Africa, we have

to do it right and do it well because we need to understand the cultural differences and what is going on in these areas. As a counseling profession, we now understand more than ever before, we can only have an effect on culture from the inside out. Our opportunity for global services to address the HIV/AIDS pandemic has increased, and this is a meaningful calling for our profession. So, to do this effectively as a profession, we need to have the cultural understanding to go and serve, and when there is no information out there to learn, we cannot do it. This is why this qualitative research has been done to provide deep insights into the intricacies of the HIV problem and the mental health counseling concerns for Ugandans living with HIV/AIDS in rural Uganda.

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## Appendix A: Interview Questions

Questions related to what it is like to be living with HIV/AIDs in rural Uganda

1. Would you share with me on how you learned you were HIV positive from initial testing to find out your results?
2. What happened after you received your HIV test results?
3. What was your life after your diagnosis?
4. Did you tell your sexual partner that are HIV positive? If yes, how did she/he react?
5. Have you told anyone else that you are HIV positive? If yes, how did they respond?
6. Have you ever been discriminated against as a result of your diagnosis? If yes, by whom?
7. What or who are your sources of support?
8. How do you describe your life?

The following questions relate to barriers to treatment

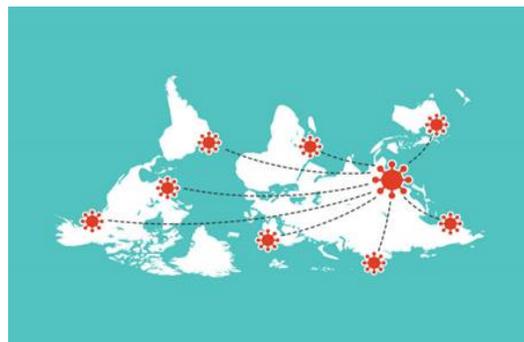
1. How has living with HIV/AIDS affected your coping skills?
2. How has living with HIV/AIDs affected your life in the village community?
3. How are you managing mentally and physically since you became aware that you have HIV/AIDS?
4. Tell me how you interact with other people in the village?
5. Could you share with me any difficulties you have in gaining treatment in your community?

6. Are there government programs that are in place to assist people who are HIV positive?
7. What else can you share with me that relates to HIV/AIDS services in your community?
8. What is the most important thing you are doing to help yourself to live with HIV/AIDS?

## Appendix B: Recruitment Flyer

Research Study:  
Exploring the Lived Experiences of HIV/AIDS in Rural Uganda

- Have you been diagnosed with HIV?
- Are you 18 years of age or older and currently on treatment at St. Mary Health Center, Kasaala?
- Are you willing to offer your time for an interview to explore and understand your HIV/AIDS experiences in rural Uganda?



- The purpose of this research study is to understand the experiences of people living with HIV/AIDS in rural Uganda through their unique stories and insights.
- This study may inform counselors, counselor educators, and the Uganda ministry of health in decisions related to this experience.

To learn more about this research study or to sign up to participate, please contact Godfrey Ddungu, MAEd, LPC, ACS, ASDCS, NCC

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This research is part of a dissertation study for the completion of the Ph.D. in Counselor Education and Supervision program at Walden University. Participants will be asked to offer 90 minutes for a meeting and interview in person.