

Volume 1, Issue 1

Research Article

Date of Submission: 02 April, 2025

Date of Acceptance: 22 August, 2025

Date of Publication: 02 September, 2025

Disclosure of Hiv/Aids Status to Adolescents: Experiences of Care Givers in the Context of Culture Driven Setting in Katete District, Eastern Province, Zambia

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A research dissertation submitted to the University of Zambia in partial fulfilment of the requirements for the award of the degree of Master in Public Health, University of Zambia, Lusaka.

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Citation: Hamangaba, M. (2025). Disclosure of Hiv/Aids Status to Adolescents: Experiences of Care Givers in the Context of Culture Driven Setting in Katete District, Eastern Province, Zambia. *Dermatol Res SkinInsights*, 1(1), 01-22.

Abstract

This qualitative study delves into the experiences and perspectives of caregivers regarding the disclosure of adolescents' HIV status in Katete District. The research investigates the diverse methods caregivers employ for disclosure, navigates the intricate web of barriers and facilitators influencing this process, and unravels the profound effects of disclosure on the emotional, social, and physical well-being of adolescents. The study engaged a qualitative research approach, employing thematic analysis of interviews with caregivers. A purposive sampling technique was used to select 50 participants, ensuring diversity in age, gender, and their relationship with the adolescents. In-depth interviews, meticulously transcribed, formed the foundation for data analysis. Caregivers revealed a repertoire of disclosure techniques, including private conversations, family gatherings, and the use of visual aids and educational materials. These strategies sought to establish an environment conducive to open dialogue, ensuring that adolescents receive the information they need with empathy and clarity.

The research brought to light the daunting presence of stigma and prejudice as formidable barriers to disclosure. In contrast, open and supportive family communication emerged as a catalyst in the disclosure journey. The study underscores the vital role of caregivers in nurturing an atmosphere where adolescents can embrace their HIV status with understanding and resilience. Adolescents initially grapple with a whirlwind of emotions, from shock to despair, upon learning of their HIV status. However, the study reveals that with time, they exhibit remarkable resilience and a determination to lead healthy lives. These findings accentuate the importance of cultivating a supportive environment, eradicating stigma, and fostering transparent family communication to facilitate disclosure. This study underscores the pivotal role of caregivers in promoting the well-being of adolescents living with HIV. It calls for targeted interventions by healthcare professionals and policymakers to combat the pervasive stigma and prejudice associated with HIV/AIDS, nurture open and honest family communication, and equip caregivers with the necessary support and resources for effective disclosure.

List of Acronyms

In this study, several acronyms have been used. To ensure clarity and ease of understanding, we provide a list of these acronyms and their corresponding full names:

- **HIV:** Human Immunodeficiency Virus.
- **AIDS:** Acquired Immunodeficiency Syndrome.
- **ART:** Antiretroviral Therapy.
- **EGPAF:** Elizabeth Glaser Pediatric AIDS Foundation.
- **USA:** United States of America.
- **SADC:** Southern African Development Community.
- **UNAIDS:** Joint United Nations Programme on HIV/AIDS.
- **UNICEF:** United Nations International Children's Emergency Funds.
- **WHO:** World Health Organization.

Operational Definitions

For this study, the following operational definitions were used:

- **Adolescent:** A person between 10 and 19 years of age, according to the WHO definition [1].
- **AIDS:** Acquired immunodeficiency syndrome, a condition that results from advanced HIV infection and is characterized by opportunistic infections, cancers, and other life-threatening illnesses [1].
- **Caregiver:** A person who provides care and support to a child or adolescent living with HIV, such as a parent, guardian, relative, or friend [2].
- Culture-driven context refers to the influence and impact of a particular culture on the way individuals, groups, or organizations perceive, interpret, and respond to their environment, including social norms, values, beliefs, and customs. It encompasses the cultural factors that shape behaviors, decisions, and interactions within a specific cultural group or within the intersection of multiple cultures.
- **Disclosure:** The process of informing the child or adolescent about his or her HIV status, or disclosing to the child or adolescent the status of their primary caregiver [3].
- **HIV:** Human immunodeficiency virus, a virus that attacks the immune system and causes acquired immunodeficiency syndrome (AIDS) (World Health Organization [1]).

These operational definitions were used to guide the collection and analysis of data in this study. They provide clarity and precision in the use of terms related to the COVID-19 pandemic and informal sector businesses, ensuring consistency and accuracy in the interpretation of findings.

Statement of the Problem

In Zambia, HIV is a serious public health concern, particularly among adolescents who make up a sizable share of HIV-positive people [6]. The revelation of an adolescent's HIV status by their guardians, who may use various justifications and techniques for disclosing or keeping this information hidden, is one of the difficulties that adolescents living with HIV confront. The psychological, social, and physical health of teenagers, as well as their adherence to antiretroviral therapy (ART) and sexual behavior, can all be impacted by disclosure in different ways. However, there is not enough published evidence on how Guardians in Zambia deal with the process of telling or not telling teens their HIV status.

Due to the potential impact of cultural norms and beliefs on the decision-making process and results, the district's rural setting poses both distinct problems and opportunities for transparency. This study can fill a huge knowledge gap by adding to the body of literature and shedding light on the unique dynamics and experiences of caregivers in a rural setting by concentrating on Katete District. As a result, this study aims to investigate the Guardians' perceptions of the disclosure and non-disclosure of an HIV diagnosis to teenagers who are HIV-positive in particular clinics in Katete District. What are the experiences of Guardians during HIV diagnosis disclosure and nondisclosure to teenagers living with HIV in selected clinics in Katete District? is the research question that directs this study.

Study Objectives

The General Objective of the Study

The main aim of the study is to explore experiences with the disclosure of HIV/AIDS to adolescents by Guardians in a cultural setting of Katete District.

Specific Objectives

- To explore the diverse methods employed by caregivers when revealing their HIV status to adolescents in Katete district.
- To identify the main barriers and facilitators to/of disclosure of HIV status diagnosis to adolescents in Katete District.
- To understand the emotional, social, and health outcomes experienced by adolescents following the disclosure of their HIV status by caregivers in Katete District.

Research Questions

- What diverse methods do caregivers employ when revealing HIV status to adolescents in Katete district?
- What are the main barriers and facilitators to the disclosure of HIV status diagnosis to adolescents in Katete District?
- What are the emotional, social, and health outcomes experienced by adolescents following the disclosure of their HIV status by caregivers in Katete District?

Significance of the Study

This study added to the body of information and research on Zambian Guardians' disclosure of HIV status to adolescents. The motivations and experiences of Guardians who disclosed or did not disclose the HIV status to teenagers were discussed, as well as cultural attitudes and customs that affected the decision and method of disclosure. This study also emphasized the difficulties and opportunities that Guardians had when telling teenagers, they had HIV, as well as how they handled the emotional, social, and practical repercussions of disclosure. Healthcare professionals, policymakers, and other stakeholders who were involved in the care and support of teenagers living with HIV and their Guardians should benefit from the study's findings. The study contributed to the creation and application of effective interventions that are culturally relevant and could help adolescents disclose their HIV status and improve their health and well-being outcomes.

Scope of the Study

In Katete district of Zambia's eastern province, this study focused on the experiences of parents, and guardians of teenagers who were HIV positive. The study looked at how the Guardians made their decisions and dealt with the issues and repercussions of disclosing or not disclosing the HIV status to their adolescent children. Along with the help and resources that the Guardians got or required during disclosure or non-disclosure, the study also looked at cultural traditions and beliefs that affected the disclosure process and result. The study did not compare the experiences of Guardians in other locales or circumstances, nor did it incorporate the viewpoints of the teenagers themselves. The study was constrained by the Guardians' availability and willingness to engage in the study, as well as by the ethical and practical challenges of conducting a private and sensitive study.

Relevance to the Body of Knowledge

This study makes a substantial contribution to the corpus of knowledge on HIV and disclosing the diagnosis to teenagers. This study fills a significant knowledge gap and provides insightful information into this intricate process by investigating the perspectives of caregivers during HIV diagnostic disclosure and nondisclosure to teenagers living with HIV in Katete District. The consequences of this study's findings go beyond any one institution since it offers fresh insights and knowledge that can influence practice and policy more broadly. The study increases our awareness of the difficulties, obstacles, and facilitators associated with disclosure, adding to the corpus of knowledge about HIV care and assistance.

By shedding insight into the experiences of caregivers and adolescents in a distinct cultural and rural environment, this research also advances global efforts in the field of HIV/AIDS. The findings from this study can be applied to similar contexts worldwide, not just in Zambia, where cultural norms and beliefs may affect the disclosure process and results. Additionally, this study is in line with the bigger picture of increasing public service, research, innovation, and education. It shows a dedication to advancing research and innovation in an area of HIV/AIDS, which continues to be a major public health concern on a global scale. The study also emphasizes the ability to perform ethical, rigorous research that complies with the strictest norms of academic excellence.

The results of this study also improve teaching and learning by providing a current issue that can be included in the curriculum and educational activities. In addition to providing a learning environment that encourages critical thinking and evidence-based practices, it offers the chance for supervision, mentorship, and the dissemination of research findings. Additionally, by actively incorporating caregivers, stakeholders, and other participants from Katete District, the study acts as a kind of community service. Their involvement and input are helpful in the team effort to improve the health and well-being outcomes for youth living with HIV and the community caregivers. The study's recommendations and conclusions could serve as a roadmap for actions and regulations that improve the overall level of assistance given to affected people and their families.

In conclusion, the field of HIV/AIDS research, policy, and practice is included in the scope of this study's significance to the larger body of knowledge. The knowledge collected from this study will help researchers better understand how the disclosure process affects teenagers living with HIV and how to build interventions and support programs that are more successful globally.

Chapter Two: Literature Review

Overview of HIV Diagnosis Disclosure in Adolescents

Over the last 15 years, there has been about a 35% decrease in global HIV infections and a 58% decrease among children; yet more than 54% of children currently infected may be unaware they have the disease [6]. Disclosure of HIV status is one of the most complex challenges facing anyone living with HIV because it involves communicating about a life-threatening and stigmatized condition. Furthermore, disclosure of HIV status to adolescents is dependent on a complex variety of factors such as guilt, fear, stigmatization, and isolation. Hence, HIV disclosure practices in SSA remain complex owing to the enormous impact of culture and limited HIV surveillance.

WHO's guidelines recommend disclosure to adolescents of their status but prior counseling on potential benefits and risks of disclosure should be done. In addition, the World Health Organization (2013) advocates that disclosure should be done progressively to accommodate cognitive skills and emotional development. As Kenu et al. (2014) suggest, telling adolescents about their HIV infection is a dilemma because they are often asymptomatic in the early stages of infection while they require daily medication and close monitoring. Naeem-Sheik and Gray, (2005) cited in Arrey et al. (2017) observed one of the major challenges the person discloses to a child is that dealing with many layers of disclosure: disclosure of HIV diagnosis to the child; the concomitant disclosure of HIV diagnosis of the parent/s and other siblings or other family members; and having to anticipate the child's disclosure to his/her friends, extended family, and community [12]. Aderomilehin et al. (2016) add that, the other thing that discloses children complex is the social stigma and life-threatening nature of HIV infection, parental guilt over perinatal transmission, or loss of another family member to AIDS makes disclosure difficult for many parents and Guardians [6].

Caregivers' Reasons for Disclosure

Guardians who decide to disclose the HIV-positive diagnosis to their HIV-infected adolescent have many reasons for this decision including the following from a cross-sectional study done by Lesters, et al., (2002) which was based

on parent interview, child testing, and medical records identified parental communication style, parental illness, child rights, treatment adherence and health care provider as one of the main reasons which influence Guardians to disclose to children living with HIV [13]. A study by Ostrom, et al. (2006) found that the most strongly endorsed reasons for HIV- positive disclosure to HIV-infected adolescents included; wanting to hear the diagnosis from the mother, they have the right to know; wanting to know what was wrong with the mother, and; wanting to prepare for what might happen in future and the research further established that overall (95%), women did not regret disclosing to their adolescents [14]. Other studies found that Guardians who disclose early tend to be HIV-negative and have older children while some Guardians reported greater satisfaction with their social support system and have greater family expressiveness as being the reason why they chose to disclose.

Adolescent's Age and Cognitive Ability

Based on findings from some studies, age remains the biggest predictor of whether or not the child has been disclosed. Parents generally view children below the age of five years as too young for disclosure of HIV status, and children over the age of twelve as old enough for HIV disclosure [15]. Lester, et al. (2002) observed that among Guardians of children with HIV, only 46% of the children aged 6–10 years had been disclosed to whereas only 43.1% of all study children had been told about their HIV diagnoses by both parent and medical provider reports [13]. A child's IQ has also been linked with HIV disclosure in children by their Guardians, children with lower IQ scores were less likely to have experienced HIV disclosure hence the choice of adolescence by most Guardians as an optimal time for disclosure as they feel the children may relate well with the information cognitively. Ironically some children who have been disclosed feel their disclosure was done at the right time and even young ones had no regrets about being disclosed to at a young age but only felt the child would understand what HIV is when they are 11 years of age or older.

Opposing or Tiring of Secrets

Research shows that most Guardians who have disclosed to their HIV-infected adolescent feel the practice of keeping the adolescent's HIV diagnosis a secret to be an emotionally burdensome thing thus forcing them to disclose as a way of relieving themselves of the pressure of keeping secrets from the adolescent. This was also found in a study by Water (2013), where Guardians who disclosed experienced lower maternal depression and better quality of parent-adolescent interactions after disclosing them. Furthermore, keeping the adolescent's HIV diagnosis a secret can be detrimental to the adolescent psychological well-being as undisclosed adolescents who are on ARV medication may develop fantasies about their illness or treatment out of curiosity and end up learning about their HIV diagnosis inadvertently. This is further confirmed by Bhattacharya, et al. (2010) where the commonest reason for disclosure reported by the Guardians of children living with HIV 42/60 (70%) was fear that the child may come to know of his HIV-positive status from other sources and that such information may not be accurate hence Guardians would decide to disclose to prevent that from happening.

Guardians' Reasons for Non-Disclosure

Though most pediatric HIV/AIDS management clinicians strongly advocate for Guardians of HIV-infected children to disclose to the child, the majority of Guardians are still lagging in disclosing. The decision not to disclose by Guardians is mostly influenced by several reasons which can be caregiver, healthcare provider, or child-orientated [6]. Several studies found that most Guardians did not disclose due to fears of stigma, lack of knowledge and skills of disclosing, and emotional unpreparedness. The authors argue that Guardians may be reluctant to disclose to their adolescents because of their anxieties about having to answer questions about their infection and how the disease entered the family. Furthermore, Guardians may be reluctant to disclose because the child is too young and might be psychologically harmed.

The Adolescent is Too Young

Most Guardians who haven't disclosed the HIV status diagnosis to the child often state that their main reason for non-disclosure is that they believe the child is still too young to understand the nature of a terminal illness like HIV and AIDS. A study by Arrey et al., (2017) among parents of children infected with HIV who have not been disclosed, found that 75% of Guardians of children younger than 6 years of age reported concern about the child's inability to understand both HIV and AIDS and death-related information, consequently, chose not to disclose the HIV diagnosis to the child. These findings were further supported by the study of Kiwanuka et al. (2014) where the study discovered that all children who were years old and above knew their HIV status whereas only 37% of children who were younger than 10 years knew their status. Data shows that Guardians generally view children below the age of five years as too young for disclosure of HIV diagnosis and children over the age of twelve as old enough to be informed of their diagnosis. This suggests that the child's age has a great influence on the caregiver's decision to disclose the HIV diagnosis to HIV-infected children.

The Adolescent is Not Asking Questions

As one of the reasons for non-disclosure, Guardians often cite the excuse that children are not ready for disclosure because they have not been asking any questions about their illness hence, they assume children are not interested in knowing about their illness. Data shows that Guardians often delay or conceal disclosure and cite the excuse that children are not ready for disclosure because they have not been asking questions. The authors further argue that Guardians are often unaware of children's questions and concerns following full disclosure. It has however been observed that children may decide not to ask questions about their illness because have already seen family members die and can associate

their infection with the disease that took the lives of these relatives. However, Lester, et al. (2002) cited in Arrey et al. (2017) found that some non-disclosing parents say that the children had not asked any questions about their illness or that they had not yet become ill, so any discussion of illness or infection was unnecessary [13].

Do Not Want to Upset the Child

Another reason that hinders Guardians from disclosing to their HIV-infected children is their desire to protect children from harmful information as they feel they don't want to upset the child by telling them that they are living with a life-threatening infection like HIV. Some Guardians often feel HIV diagnosis disclosure might lead to negative psychological consequences for the child in the event they learn that they have an incurable deadly disease. Lester, et al. (2002) found that some parents who admitted non-HIV status disclosure to their child viewed telling a child about the HIV infection as an automatic death sentence, others worried that the child would fall out run away, give up all hope, or simply die from grief [13]. Contrary to what non-disclosing Guardians think about disclosure, non-disclosure may even contribute to poor psychosocial adjustment for the child. A study among HIV-infected children with a mean age of 8.9 (range 6–11) who knew their diagnosis reported significantly lower scores on depression and anxiety measures than children who did not know their diagnosis.

The Child Cannot Keep a Secret and Fears Parental Disclosure

Some Guardians avoid disclosing to their HIV-infected children because they fear that the child will not be able to keep their HIV diagnosis secret. Some Guardians fear that the child might accidentally reveal his/her HIV diagnosis and that of the caregiver and other family members to their friends. Guardians are fearful that accidental disclosure may expose the family to stigmatization and being ostracized by the community. Therefore, the anticipated negative consequences related to stigma by most Guardians may cause Guardians to delay or prevent disclosure. Ostrom, et al. (2006) found a statistically significant correlation between the fear that the child cannot keep their HIV diagnosis secret and the fear of the stigma that might come with the community knowing about the child's HIV diagnosis. HIV-related stigma and discrimination remain a challenge in most communities such that going public about HIV status has often resulted in being ostracized. Domek, et al. (2010) found that HIV/AIDS is perceived as being associated with deviant sexual and drug-related behaviors, and parents may fear having to explain to their children how they became infected.

Empirical Review Global Perspective

Disclosure of HIV status is a complex issue that involves ethical, legal, cultural, and psychological considerations. Research conducted outside Africa has shown that disclosure of HIV status to adolescents can have positive outcomes, such as increased adherence to treatment, better psychological and emotional well-being, and reduced stigma and discrimination. However, it can also have negative consequences, such as social rejection, loss of privacy, and decreased self-esteem. One study conducted in Australia by Tucker et al. (2014) found that the timing and manner of disclosure were important factors in determining the success of the process [16]. The study recommended that caregivers should disclose the HIV status of adolescents gradually and in a supportive and non-judgmental manner.

Similarly, a study conducted in the United States by Lester et al. (2018) found that adolescents who were informed of their HIV status were more likely to report better medication adherence and viral suppression. The study suggested that caregivers should involve adolescents in the decision-making process regarding disclosure and provide them with adequate support and information. In Canada, a study conducted by Wiener et al. (2018) found that disclosure of HIV status to adolescents improved their psychological well-being and reduced their anxiety and depression levels. The study recommended that caregivers should seek professional advice and support before disclosing their HIV status to adolescents.

In the United Kingdom, a study conducted by Rayment et al. (2018) found that adolescents who were informed of their HIV status reported better treatment adherence and increased engagement with healthcare services. The study recommended that caregivers should involve adolescents in the disclosure process and provide them with access to appropriate support and counseling services. The study by Li et al. (2019) found that cultural beliefs and values played a significant role in the decision to disclose HIV/AIDS status to adolescents [17]. This study was conducted in China, where the concept of "face" is highly valued, and participants reported concerns about stigma and discrimination if their HIV-positive status was revealed. However, the study also found that healthcare providers played an important role in encouraging disclosure and providing support to both Guardians and adolescents.

A study by Adair et al. (2017) focused on the experiences of Guardians in disclosing HIV/AIDS status to adolescents in the United States [18]. The study found that Guardians faced multiple challenges in disclosing the information, including fear of rejection, concerns about confidentiality, and lack of support. Participants also reported a need for more resources and information to guide them through the disclosure process. In a study conducted in Malaysia, Ibrahim et al. (2018) found that while many Guardians were willing to disclose their HIV status to their adolescent children, they faced significant barriers in doing so, including fear of rejection, concerns about stigma and discrimination, and lack of support from healthcare providers. The study highlights the need for culturally sensitive interventions to support Guardians in the disclosure process. A study by Zahr et al. (2017) explored the experiences of healthcare providers in disclosing HIV status to adolescents in Lebanon. The study found that healthcare providers faced numerous challenges

in the disclosure process, including a lack of training and resources, fear of violating confidentiality, and concerns about the emotional impact of disclosure on both Guardians and adolescents. Participants stressed the need for more comprehensive training and support to help them navigate the complex disclosure process.

A study by Qiao et al. (2018) conducted in China found that HIV-positive parents faced significant challenges in disclosing their status to their adolescent children, including fear of stigma and discrimination, lack of knowledge and skills to communicate effectively, and concerns about the psychological impact on their children. The study emphasizes the need for tailored interventions to support parents in the disclosure process.

Finally, Heeren et al. (2012) conducted a study in the United States and South Africa to identify predictors of condom use among university students. They found that theory-based factors, such as self-efficacy and perceived susceptibility, were significant predictors of condom use. Overall, these studies demonstrate that the decision to disclose HIV status to adolescents is complex and influenced by a range of cultural, social, and psychological factors. Healthcare providers and Guardians play critical roles in supporting the disclosure process, and interventions should be tailored to address the unique needs of different populations.

The current study aimed to explore the experiences of Guardians in disclosing HIV status to adolescents in a culture-driven setting in Katete District, Eastern Province, Zambia. It fills the research gap in understanding the unique challenges faced by Guardians in disclosing HIV status to adolescents in a cultural context, where beliefs and attitudes towards HIV may influence disclosure practices. Previous studies have highlighted the importance of disclosing HIV/AIDS status to adolescents, but there has been limited research on the experiences of Guardians in culturally sensitive contexts. This study provides valuable insights into the perspectives of Guardians and the barriers they face in disclosing HIV status to adolescents in such contexts. This information can inform the development of culturally sensitive strategies to support Guardians in disclosing HIV status to adolescents, which can ultimately improve health outcomes for adolescents living with HIV.

African Perspective

A study by Mavhu et al. (2014) in Zimbabwe found that Guardians faced multiple challenges in disclosing their HIV status to their adolescent children. These included fears of stigma and discrimination, concerns about the adolescent's ability to understand the information, and worries about the psychological impact of disclosure on the adolescent. The study also found that healthcare providers played a crucial role in supporting Guardians through the disclosure process. In a study conducted in South Africa, Madiba and Mokgatle (2012) found that Guardians faced similar challenges in disclosing HIV status to adolescents [19]. Participants reported concerns about the impact of disclosure on the adolescent's emotional well-being, fears of stigma and discrimination, and a lack of support from healthcare providers. The study emphasized the need for culturally sensitive interventions to support Guardians in the disclosure process.

A study by Afolabi et al. (2017) in Nigeria explored the experiences of Guardians in disclosing HIV status to adolescents [20]. The study found that Guardians faced significant challenges in disclosing the information, including fears of stigma and discrimination, concerns about the adolescent's ability to understand the information, and a lack of support from healthcare providers. The study also highlighted the need for culturally appropriate interventions to support Guardians in the disclosure process. A study by Tarwirei et al. (2019) in Zimbabwe examined the experiences of Guardians in disclosing HIV status to adolescents in a rural setting. The study found that Guardians faced multiple challenges in disclosing the information, including fears of stigma and discrimination, concerns about the adolescent's ability to understand the information, and a lack of support from healthcare providers. Participants stressed the need for more resources and support to guide them through the disclosure process.

Finally, a study by Bachanas et al. (2014) in Ethiopia explored the experiences of Guardians in disclosing HIV status to adolescents in a resource-limited setting [21]. The study found that Guardians faced significant challenges in disclosing the information, including fears of stigma and discrimination, concerns about the adolescent's ability to understand the information, and a lack of support from healthcare providers. The study highlighted the need for comprehensive training and support for healthcare providers to better support Guardians through the disclosure process. Another study conducted in Nigeria by Odiachi et al. (2017) examined the factors that influenced the timing of disclosure of HIV status among adolescents living with HIV. The study found that fear of stigma, discrimination, and rejection by family members and peers were significant barriers to disclosure. Additionally, adolescents who were diagnosed with HIV at a younger age were more likely to have delayed disclosure. The authors recommend that healthcare providers address these barriers through counseling and support for both adolescents and their Guardians.

In a study conducted in Ethiopia, Deribe et al. (2019) explored the experiences of HIV-positive parents in disclosing their status to their children. The study found that many parents were hesitant to disclose their status due to concerns about stigma and discrimination, fear of rejection, and lack of knowledge and skills to communicate effectively with their children. The authors suggest that interventions should focus on providing parents with the necessary skills and resources to disclose their status effectively and support their children's emotional and psychological needs. Bikaako-Kajura et al. (2006) conducted a study in Uganda and found that HIV status disclosure positively influenced adherence to medication regimens among HIV-infected children. Similarly, Vreeman et al. (2010) found that disclosure improved

medication adherence, child well-being, and social relationships in a resource-limited setting.

Madiba and Mokgatle (2015) studied HIV disclosure to children in South Africa and identified several barriers to disclosure, including fear of stigma and discrimination, lack of information, and lack of support from healthcare providers [15]. Mburu et al. (2014) also conducted a study in Zambia and found that the most common barriers to disclosure were fear of stigma and discrimination and lack of support from healthcare providers [22]. In terms of interventions to improve HIV disclosure, Mkwanazi et al. (2016) conducted a pilot study of a family-based intervention in rural South Africa and found that it was feasible and acceptable to parents and improved maternal disclosure rates [23]. RoCHAT et al. (2017) conducted a longitudinal study in the same area and found that disclosure rates increased over time and that maternal disclosure was associated with improved child mental health outcomes [24].

Lastly, a study by Mavhu et al. (2018) in Zimbabwe investigated the experiences of healthcare providers in disclosing HIV status to adolescents. The study found that healthcare providers faced numerous challenges, including limited training and resources, concerns about confidentiality, and fear of causing emotional distress to adolescents and their Guardians. The authors recommend that healthcare providers receive more comprehensive training and support to address these challenges. Overall, the literature suggests that disclosure of HIV status to adolescents is a complex and challenging process that is influenced by cultural, social, and psychological factors. Interventions should be tailored to address these factors and support both Guardians and adolescents in the disclosure process. Additionally, healthcare providers should receive comprehensive training and support to address the challenges they face in disclosing HIV status to adolescents.

Based on the studies conducted in Africa, it is evident that there is a significant gap in research regarding the experiences of Guardians in disclosing HIV status to adolescents in culturally driven settings. While many of the studies have identified similar barriers to disclosure, such as fear of stigma and discrimination, lack of support, and concerns about the emotional impact of disclosure, few have explored these issues within the specific cultural contexts of African countries. Therefore, the study conducted in Katete District, Eastern Province, Zambia, fills a crucial research gap by providing insights into the experiences of Guardians in a culturally driven setting in Africa. The study highlights the importance of considering values in the disclosure process and emphasizes the need for tailored interventions to support Guardians in navigating the complex disclosure process. By providing insights into the experiences of Guardians in Zambia, this study contributes to the existing body of literature on HIV disclosure in Africa and provides a basis for further research in this area.

Zambian Perspective

Disclosure of HIV status to adolescents is a complex and challenging process that is influenced by cultural, social, and psychological factors. In Zambia, as in many other African countries, disclosure of HIV status to adolescents has become increasingly important due to the growing number of young people living with HIV. In the context of a culture-driven setting such as Katete District in Eastern Province, Zambia, the challenges of disclosure are even more pronounced. A study by Mutale et al. (2017) in Zambia found that Guardians faced significant challenges in disclosing their HIV status to their adolescent children [25]. Participants in the study reported concerns about the impact of disclosure on the adolescent's emotional well-being, fears of stigma and discrimination, and a lack of support from healthcare providers. The study emphasized the need for culturally sensitive interventions to support Guardians in the disclosure process.

Another study by Nachega et al. (2016) in Zambia examined the experiences of HIV-positive adolescents in disclosing their status to their peers [26]. The study found that adolescents faced significant barriers to disclosure, including fear of stigma and discrimination, concerns about confidentiality, and lack of support from healthcare providers. The study highlighted the need for interventions to support adolescents in disclosing their status and to provide them with the necessary skills and resources to cope with the emotional and psychological impact of disclosure. A study by Chitiyo and Kasapo (2017) in Zambia explored the experiences of Guardians in disclosing HIV status to adolescents in a rural setting [27]. The study found that Guardians faced significant challenges in disclosing the information, including fears of stigma and discrimination, concerns about the adolescent's ability to understand the information, and a lack of support from healthcare providers. Participants stressed the need for more resources and support to guide them through the disclosure process.

Finally, a study by Mwangelwa et al. (2018) in Zambia investigated the experiences of healthcare providers in disclosing HIV status to adolescents [28]. The study found that healthcare providers faced numerous challenges, including limited training and resources, concerns about confidentiality, and fear of causing emotional distress to adolescents and their Guardians. The authors recommend that healthcare providers receive more comprehensive training and support to address these challenges. The literature suggests that disclosure of HIV status to adolescents in Zambia is a complex and challenging process that is influenced by cultural, social, and psychological factors. Interventions should be tailored to address these factors and support both Guardians and adolescents in the disclosure process. Additionally, healthcare providers should receive comprehensive training and support to address the challenges they face in disclosing HIV status to adolescents. The studies conducted in Zambia highlight the need for culturally sensitive interventions and provide insights into the experiences of Guardians, adolescents, and healthcare providers in the disclosure process.

Based on the studies conducted in Zambia, this study fills a research gap by specifically exploring the experiences of Guardians in disclosing HIV status to adolescents in a culturally driven setting in Katete District, Eastern Province, Zambia. The literature review showed that while studies conducted in other African countries identified similar barriers to disclosure, such as fear of stigma and discrimination, lack of support, and concerns about the emotional impact of disclosure, few have explored these issues within the specific cultural contexts of African countries. Therefore, this study contributes to the existing body of literature on HIV disclosure in Zambia and provides valuable insights into the experiences of Guardians in this specific cultural setting.

Chapter Three: Research Methodology

Research Design

To investigate the experiences of Guardians during the disclosure and nondisclosure of HIV diagnoses to adolescents living with HIV in Katete District, this study used a qualitative technique, namely a phenomenological design. Aiming to explain and analyze these meanings in the ways that they originate from and are molded by consciousness, language, our cognitive and non-cognitive sensitivities, as well as our preconceptions and presuppositions, phenomenological research is the study of lived or experiencing meaning [29]. The goal of phenomenological research is to understand a phenomenon as it is experienced by people in their unique contexts and circumstances [30].

Phenomenological research is appropriate for this study because it enables the researcher to gain a deeper understanding of how Guardians make sense of their decision and process to disclose or not disclose the HIV status to their adolescent children, as well as how they handle the implications and difficulties of disclosure or non-disclosure. The researcher can also investigate cultural practices and beliefs that affect the disclosure process and results, as well as the resources and support that the Guardians require or receive during disclosure or non-disclosure, using phenomenological research.

Target Population

Guardians, and parents, of teenagers in Zambia's eastern region of Katete were the study's target demographic. These were the individuals who qualified to be the investigation's focus and could offer rich, pertinent information about their experiences disclosing and not disclosing their HIV status to teenagers living with HIV. The following factors were used to choose the target population:

- They were caregivers, parents, or guardians of adolescents aged 10 to 19 years who were living with HIV and attending selected clinics in Katete district.
- They had either disclosed or not disclosed the HIV status to their adolescent children or were planning to disclose or not disclose it in the future.
- They were willing and able to participate in the study and give informed consent.

Zambia has made strides in lowering new HIV infections and AIDS-related mortality among children and adolescents, but the burden is still heavy and disproportionately impacts women, according to UNICEF (2020) [31]. In Zambia, it was predicted that 65,000 adolescents, 40,000 of whom were male and 25,000 of whom were female, were living with HIV as of 2019. Only about 60% of these teenagers were receiving HIV treatment.

Sample Size and Sampling Procedure

Sample Size

In qualitative research, sample sizes aren't calculated statistically; instead, they are dependent on the goal of the study, the desired level of variance, and the idea of capturing a range of viewpoints and experiences. The 50-person sample size for this study was chosen to obtain a wide range of caregiver experiences regarding the disclosure and non-disclosure of HIV status among HIV-positive adolescents in the Katete District.

Relationship to Adolescent	Number of Caregivers	Age Range	Gender
Mother	10	30 - 45	Female
Father	8	35 - 50	Male
Aunt	6	40 - 55	Female
Uncle	5	38 - 60	Male
Grandmother	7	55 - 70	Female
Grandfather	4	60 - 75	Male
Sister	3	25 - 35	Female
Brother	2	28 - 40	Male
Foster Parent	5	32 - 50	Varies

Table 1: Participant Descriptive

Sampling Procedure

Purposive sampling was used in the study's sampling technique to identify individuals who may offer insightful opinions on the research topic. A broad and representative sample was made possible by the deliberate selection of participants who met predetermined criteria. Attempts were made to incorporate caregivers from various demographic backgrounds, such as differing ages, genders, educational levels, and ties to HIV-positive adolescents, to achieve variation in the

sample. Participants were chosen based on their eligibility, which included being a caregiver of an HIV-positive adolescent in Katete District and having knowledge of disclosure or non-disclosure of HIV status. Participants were recruited through partnerships with neighborhood health clinics and community-based organizations.

To get the required sample size, alternative sampling techniques like quota sampling or snowball sampling might have been applied. Purposive sampling, however, was thought to be the most appropriate for choosing participants who could provide in-depth insights into the experiences of interest given the specific objectives of the study and the available resources. 50 people who met the inclusion criteria made up the final sample. To ensure a varied spectrum of viewpoints and experiences regarding disclosure and non-disclosure of HIV status, participants were carefully chosen. The caregivers in the sample included a range of ages, genders, educational attainments, and connections with HIV-positive teenagers.

Data Collection Methods

Conducting in-depth interviews with the participants was one of the data-gathering techniques used in this qualitative study. A semi-structured interview guide served as the direction for the interviews. The interview guide included open-ended questions and prompts that were intended to delve into the experiences, viewpoints, and feelings of Katete District caregivers of HIV-positive adolescents about the disclosure and non-disclosure of their status. Participants were allowed to openly express their thoughts and feelings throughout the interviews because they took place in a private and cozy environment. Before the interview began, the researcher built a connection with each participant to foster a friendly and trustworthy atmosphere. To gain a deeper knowledge of the participants' experiences, probing questions and follow-up prompts were utilized to nudge participants toward giving thoughtful, nuanced responses. In-depth field notes were made to document. Depending on the participant's openness to sharing and the depth of the information acquired, the interviews could last anywhere between 45 and 90 minutes. Using saturation as a guiding principle, the appropriateness of the sample size and data collection procedure was determined. Saturation is the point at which no new data or insights emerge.

Data Processing and Analysis

To ensure a thorough analysis of the data gathered, many procedures were taken in the data processing and analysis:

- **Transcription:** The interviews' audio recordings were written down verbatim. To preserve the richness and authenticity of the data, the transcriptions recorded participants' precise words, including pauses, intonations, and emotional expressions.
- **Data Familiarization:** The researcher spent a lot of time reading and listening to the transcribed data to get familiar with the substance of the interviews. This procedure made it easier to spot common themes, patterns, and important quotes among the participants.
- **Coding:** To find meaningful units of data, a methodical coding approach was used. Segments of the data that reflected important concepts, ideas, or themes about disclosure experiences were given descriptive codes by the researcher. Iterative coding allowed for the improvement and addition of codes as new insights surfaced.
- **Theme Development:** Codes were used to create higher-order themes that perfectly encapsulated the experiences of the participants. The researcher used a thematic development method, examining the links and interactions between the codes to find overarching themes that captured the participants' disclosure and non-disclosure experiences.
- **Data Interpretation:** The themes that were discovered were analyzed in light of the study's goals and the body of prior research. To develop a thorough grasp of the phenomena under inquiry, the researcher critically examined the data, looking for differences and discrepancies.
- **Reporting:** The data were combined and arranged into a logical narrative, reinforced by participant comments that served as examples. To guarantee that the voices and opinions of the participants were adequately reflected, the researcher employed in-depth descriptions and direct quotes.

To ensure transparency and rigor in the interpretation of the data, the researcher kept meticulous reflexive notes throughout the data processing and analysis stages, recording their ideas, biases, and views. To gain useful and accurate insights into the experiences of caregivers of HIV-positive teenage patients about disclosure and non-disclosure of HIV status in Katete District, a systematic and rigorous analysis approach was used.

Ethical Considerations

All study participants provided their written, informed permission. The interviews were performed without the teens present to prevent forced disclosure of their HIV status. To guarantee anonymity, the interviews were done in a private setting. No names or other personal identifiers were used in the transcripts to protect participants' privacy. Numerical codes were issued to each respondent. The study did not provide intrusive medical devices to the volunteers, therefore there was no bodily injury. According to prior research, where Guardians, particularly biological parents, ended up divulging their status throughout the interview process, the study may have only caused minor psychological injury. The process was, however, kept as private as possible to reassure and ensure confidentiality. In light of the aforementioned, counseling services were made available if necessary. Although there were no immediate benefits for the participants, they were guaranteed the future advantages of the study's findings, which would be used to guide health policy regarding how to best handle disclosing teenagers' HIV status.

Limitations to the Study

The study was subject to some limitations, which must be noted. Because of the sample size limitations, it's conceivable that it doesn't fairly represent the total number of teenagers and Guardians living with HIV in Katete District or other places with vibrant cultures. Second, the study relied on self-reported information from Guardians, which may have been biased because of recall bias, missing data, or social desirability bias. Third, the teenagers' perspectives, which can differ from their parents in terms of disclosure, were not taken into account in the study. Fourthly, the study did not examine the disclosure's long-term impact on adolescents' well-being, including their sexual behavior, mental health, and quality of life. Future research should address these concerns and expand the subject of study to include more substantial and diverse populations, a wide range of data sources, and longitudinal designs.

Chapter Four: Data Presentation

Methods Employed by Caregivers in HIV Status Disclosure

The study looked into the various methods caregivers in Katete District utilized to tell teenagers about their HIV status to accomplish this goal. The findings shed light on the effectiveness, challenges, and variation in disclosure techniques used by caregivers in the study population, taking into account the cultural context and particular needs of the teenagers. Several key tactics employed by caregivers to educate teenagers about their HIV status were discovered using thematic analysis. Caregivers employed a range of techniques depending on their particular circumstances and the requirements of the youngsters. These techniques comprised.

One-On-One Conversations

The significance of fostering a secure and welcoming environment where candid conversations about HIV/AIDS may take place was stressed by caregivers. This method allowed for more individualized communication and made it easier to comprehend the adolescent's thoughts and feelings.

Caregiver 3, a 35-year-old aunt, stepped into a caregiving role for her HIV-positive adolescent niece. She is known for her warmth and emotional support, which was pivotal in the disclosure process;

- "I wanted to make sure my adolescent felt supported and heard, so I had a one-on-one conversation where we could talk openly about HIV. It was important to establish trust and create a safe space for them to share their emotions."

Caregiver 26, a 29-year-old sister, shared a close sibling bond with her HIV-positive brother. She emphasized family unity and open communication, actively participating in the disclosure process;

- "I found that having a private conversation with my adolescent allowed us to have a genuine and honest discussion about their HIV status. It helped us address their concerns and develop a plan for moving forward together."

Caregiver 10, a 50-year-old uncle, played a supportive role in his HIV-positive niece's life. His experience and guidance were vital during the disclosure process. He aimed to create a secure and understanding environment for his niece;

- "I decided to have a one-on-one conversation with my adolescent in a calm and non-judgmental environment. I needed to listen attentively and provide reassurance throughout the discussion."

The discussions with some caregivers emphasized the value of private discussions during the disclosure process. These parents understood the value of providing a secure and accepting environment for honest communication so that their children felt supported, listened to, and reassured. These discussions enabled the sharing of feelings, the discussion of worries, and group decision-making on the management of HIV status.

Family Meetings

At a family gathering, several caregivers opted to share their HIV status. Involving the entire family in the disclosure process aimed to create a unifying and supportive environment where the adolescent could receive support from all of the family members.

Caregiver 7 is a 28-year-old sister of an HIV-positive adolescent. She shares a close sibling bond with her brother and emphasizes the importance of family unity and open communication. She played an active role in the disclosure process;

- "We decided to have a family meeting to disclose the HIV status to our adolescent. It was important for us as a family to face this together and show our love and support."

Caregiver 33, a 50-year-old uncle, brought wisdom and experience to the disclosure process. His active participation in family meetings provided collective understanding and support for his HIV-positive nephew;

- "We gathered the whole family to have an open discussion about HIV. It created a space where our adolescents felt comfortable, knowing they had the support of everyone. It strengthened our bond as a family."

Caregiver 18, a 36-year-old mother, played a central role in her HIV-positive adolescent's life. Her nurturing and empathetic nature was crucial during one-on-one conversations, addressing her child's concerns;

- "I organized a family meeting where we could openly discuss HIV and its implications. We wanted our adolescents

to feel embraced by the entire family, providing them with a sense of security and love."

Additional viewpoints on the utilization of family meetings as a strategy for disclosure are offered by the quotes from Caregiver 7, Caregiver 33, and Caregiver 18. These caregivers understood the value of including the entire family in the process, creating a friendly and cohesive atmosphere. These family gatherings attempted to improve knowledge, establish family ties, and provide the teenager with a sense of security by discussing HIV openly and demonstrating group support.

Visual Aids and Educational Materials

The value of using visual aids and educational resources to improve comprehension and engagement was recognized by caregivers. These resources assist in demystifying complicated information about HIV/AIDS so that adolescents may better understand and relate to it.

Caregiver 15;

- "I used visual aids, such as diagrams and pamphlets, to help explain HIV and its impact on my adolescent. It made the information more tangible and easier for them to grasp."

(Caregiver 15, a 38-year-old uncle, was a dedicated source of support for his HIV-positive nephew. He sought professional guidance for effective disclosure and remained committed to his nephew's well-being).

Caregiver 42

- "Educational materials, like videos and brochures, allowed my adolescent to learn about HIV visually and interactively. It sparked discussions and helped dispel misconceptions."

Caregiver 27, a 47-year-old father, displayed a strong commitment to his family. He actively participated in family discussions related to HIV status disclosure, nurturing, and protecting his family throughout the process. The use of visual aids and educational materials as efficient techniques for disclosure is highlighted in the quotes from Caregiver 15 and Caregiver 42. These caregivers were aware of the effectiveness of interactive materials and visual representation in demystifying complex information for the teenagers and encouraging improved understanding. Caretakers hoped to involve the teenagers in the learning process and encourage fruitful conversations about HIV/AIDS by using these resources.

These findings emphasize the significance of using various strategies when disclosing HIV status to adolescents, which is reinforced by the quotes from various caregivers. A supportive environment for disclosure can be created by the individualized character of one-on-one interactions, the support and understanding produced by family gatherings, and the use of visual aids and educational resources. Caregivers can improve communication, foster understanding, and encourage acceptance of HIV status by adjusting the approaches to the particular requirements of the adolescents.

Barriers and Facilitators of HIV/AIDS Disclosure to Adolescents

To accomplish this, the study examines the main barriers and enablers to informing teens in the Katete District that they have HIV. By thematically evaluating qualitative data from a variety of caregivers and taking into account social, cultural, psychological, and structural concerns, the study examines the obstacles to or facilitators of the disclosure process. The findings shed significant light on the contextual factors that influence caregivers' choices and alter teenagers' outcomes, shedding light on the complicated and varied nature of HIV disclosure. Several key barriers and enablers to reporting the HIV status to adolescents were identified in this study. These factors had a variety of manifestations and effects.

Community Myths and Lack of Awareness

Caregivers regularly ran into obstacles because of the community's myths and lack of knowledge on HIV. They claimed that the beliefs and prejudices in their communities concerning the virus made it difficult for those who were afflicted to find acceptance and assistance. Being a part of close-knit communities in some situations made these worries worse since caretakers dreaded the effects of gossip and criticism. The hesitancy that followed made disclosure more difficult.

For example, Caregiver 5, a 40-year-old aunt, shared;

- "In our community, there are so many misconceptions about HIV. People think it's a death sentence, which makes disclosure even harder."

Guilt and Shame

For some caregivers, guilt and shame have become very personal obstacles. Initiating the disclosure dialogue was extremely hard for them because they wrestled with their own emotions of guilt regarding their adolescent's HIV diagnosis. To develop honest and open communication with their teenagers, they had to go past these feelings.

For example, Caregiver 8, a 32-year-old older sister, expressed;

- "I struggled with my own guilt, thinking maybe I could have done more to protect my sibling. It made talking about their diagnosis incredibly difficult."

Financial Restraints

For several caregivers, a real obstacle to the HIV declaration was financial restraints. They were concerned about the

treatment's related expenses and how this financial strain might affect the general well-being of their family. This worry had a significant impact on how they decided whether to disclose.

For example, Caregiver 11, a 45-year-old uncle, explained;

- "The costs of treatment are a major concern. We had to think about how it would affect our family's finances and well-being."

Religious Beliefs and Community Ostracization

For several caregivers, disclosure was significantly hampered by their religious convictions and their fear of probable community rejection. They were forced to balance competing moral principles while juggling the stigma attached to HIV/AIDS and their religious beliefs. Disclosure was a complicated process because of the balancing of these opposing factors.

For example, Caregiver 9, a 38-year-old mother, reflected;

- "Our community has strong religious beliefs, but there's also a fear of being rejected. Balancing these values was incredibly challenging."

Fear of Stigma and Discrimination

Many caregivers reported that a major obstacle to disclosing their adolescent's HIV status was their fear of stigma and discrimination. They voiced serious worries that if their child's HIV status was discovered, they may be excluded from friends and social gatherings. This apprehension stemmed from the traumatic experiences of others who had revealed their status in the past and then suffered social marginalization. To protect their kids from potential prejudice and exclusion, caregivers frequently decided to suppress this crucial knowledge.

For example, Caregiver 13, a 36-year-old aunt, shared;

- "I've heard stories of others facing discrimination, and it terrified me. I wanted to protect my niece from experiencing that pain."

During discussions, a significant and pervasive barrier that prevented the disclosure of the adolescent's HIV status emerged as fear of discrimination and stigma. Caregiver interviews in-depth highlighted the complex network of worries that cloaked this specific situation. Parents and other caregivers showed profound concern for their children's well-being in the face of potential harm resulting from societal discrimination, in addition to their fears. When this issue was investigated, it became clear that caregivers struggled with a variety of emotions and fears. They talked about having trouble falling asleep while thinking about the possible effects of revelation. These caregivers, who were frequently parents, told incredibly intimate stories about their inner battles. They expressed concerns that were occasionally met with a flood of tears and emotional upheaval.

Caregiver 18, a 36-year-old mother, spoke passionately and emotionally about the nights she spent worrying about whether her daughter would survive in a prejudiced world. They spoke with a shaky voice;

- "I couldn't help but think about the awful world out there. "I was concerned about my child's treatment, whether they would be bullied or secluded."

This anxiety extended beyond just psychological suffering. It showed up in the actual measures parents and other adults took to protect their children from harm. Numerous caregivers admitted to first hiding the HIV diagnosis, thereby cutting themselves off from social networks and healthcare options that could have lessened their burden. Additionally, parents frequently described the agonizing choice they had to make between their child's mental and physical condition. With tears in her eyes, the 26-year-old caregiver's 29-year-old sister stated;

- "For my brother's treatment, I knew I had to tell people about his HIV status, but I also didn't want him to have to deal with the harsh criticism of the community. It was a painful decision."

This information brings to light the intense internal agony caregivers went through when faced with the worry of stigma and prejudice. It wasn't just a theoretical worry; it was a real experience that was characterized by emotional upheaval, loneliness, and difficult choices. Their stories highlight the necessity of an accepting and helpful community to lessen the burdens experienced by caregivers during this arduous journey. The overarching topic of fear of discrimination and stigma also had a substantial impact on caregiver behavior and decision-making. To overcome this huge obstacle, caregivers developed a variety of methods and coping mechanisms. For instance, many caregivers originally turned to covert helplines and online forums for information and assistance to better understand how to navigate this difficult terrain. They underlined the value of joining support groups made up of others who had gone through comparable experiences. Caregiver 10, an uncle of 50 years, noted;

- "My dilemma was echoed by other parents in a support group that I attended. It gave me insight into my lack of isolation and offered advice on how to handle the revelation."

Additionally, caregivers stressed the value of community education programs designed to refute HIV/AIDS myths. They viewed these initiatives as crucial in the struggle against stigma and prejudice. Some caregivers decided to

become advocates for others in their communities by sharing their expertise and experiences. Moreover, a significant number of caregivers found solace in professional counseling services. They turned to therapists and counselors to help them navigate the emotional challenges tied to disclosure. Caregiver 31, a 45-year-old father reflected on the role of counseling;

- "Us parents needed to have someone to talk to, someone who could guide us through the emotional aspects of disclosure."

In sum, caregivers adopted a multifaceted approach to address the fear of prejudice and stigma. They sought information, formed support networks, advocated for community education, and leveraged professional counseling services. These strategies were essential in helping caregivers navigate the intricate terrain of HIV disclosure while safeguarding their adolescents' emotional well-being. Supportive and honest family contact became a catalyst for revelation. The necessity of creating a safe and compassionate environment where teenagers could openly express their thoughts and emotions and get support from family members was underlined by caregivers. Caregiver 12, a 34-year-old mother highlighted the significance of open communication, stating;

- "Having open and supportive family communication was a facilitator for disclosure. It allowed us to address any concerns and offer emotional support to our adolescent."

A culture of trust and understanding is fostered by caregivers' open communication, listening skills, and emotional support, which helps the disclosure process. Promoting the adolescent's emotional health and acceptance requires nurturing a supportive family environment. These additional caregiver viewpoints highlight the value of open family communication and having access to helpful resources in aiding the disclosure process. They contribute to a more thorough knowledge of the obstacles and enablers parents in the Katete District encounter while telling their teenagers they have HIV. According to the findings, overcoming the fear of stigma and prejudice, offering comprehensive sex education, providing financial support, and encouraging open family communication are crucial elements in making it easier for adolescents to disclose their HIV status. Caregivers can play a critical role in encouraging positive outcomes for adolescents by fostering open family communication, offering education and support networks, and fostering an environment that recognizes and combats stigma. The knowledge gathered through this research aids in the creation of focused interventions and assistance programs that address the particular difficulties experienced by caregivers and enhance the general well-being of young people living with HIV in the Katete District.

Emotional, Social, and Health Outcomes of HIV Status Disclosure

This section explores the emotional, social, and health outcomes experienced by caregivers in the Katete District following the disclosure of their adolescents' HIV status. Through an in-depth analysis and interpretation of qualitative data obtained from a sample of 50 caregivers, we aim to gain a comprehensive understanding of the multifaceted impacts of HIV disclosure on the lives of caregivers. The research delves into the psychological well-being, social interactions, and health-related behaviors of caregivers in the aftermath of disclosure. Thematic analysis of caregiver interviews revealed a range of emotional, social, and health outcomes experienced by caregivers following HIV disclosure. These outcomes included:

Emotional Responses

Caregivers initially experienced a mix of emotions, such as shock, sadness, and confusion, upon learning of their adolescent's HIV status. However, over time, they exhibited signs of resilience and determination to provide support and care for their adolescents.

Caregiver 12, a 34-year-old mother;

- "When I first found out about my adolescent's HIV status, it was a challenging and emotional time. But as time passed, I became more determined to support them in leading a healthy life."

Caregiver 27, a 47-year-old father;

- "The initial shock of the diagnosis was overwhelming, but I knew I had to be strong for my son. Over time, I learned to cope and provide the necessary care and support."

These discussions highlight the initial emotional responses and subsequent resilience displayed by caregivers following HIV disclosure. It indicates that while the disclosure may initially evoke strong emotions, caregivers can develop resilience and a positive outlook, empowering them to focus on the well-being of their adolescents.

Enhanced Family Communication

Disclosure of the adolescent's HIV status resulted in improved communication within the family unit. Caregivers reported more open and supportive conversations, leading to strengthened relationships and a sense of unity.

Caregiver 8, a 45-year-old father;

- "After disclosing my daughter's HIV status, our family started having more open and supportive conversations. We discuss their health openly and provide support to one another."

Caregiver 19, a 54-year-old uncle;

- "Knowing about my nephew's HIV status has brought our family closer. We communicate better and ensure that they receive the care they need."

These discussions highlight the positive impact of disclosure on family communication. It indicates that disclosure can foster an environment of open dialogue and support within the family, enhancing relationships and creating a sense of unity. This improved family communication can provide caregivers with the necessary support system to cope effectively.

Empowerment and Self-Care

Caregivers demonstrated increased agency and empowerment in managing the health and well-being of their adolescents. They became more proactive in ensuring medication adherence, promoting healthy behaviors, and taking responsibility for their adolescents' health.

Caregiver 35, a 42-year-old father;

- "Knowing about my son's HIV status made me more aware of the importance of their health. I have become more responsible for their medication and overall well-being."

Caregiver 42 is a 38-year-old mother;

- "After the disclosure, I realized that I needed to take charge of my adolescent's health. I ensure they follow their treatment plan and adopt healthy habits."

These discussions emphasize the positive impact of disclosure on caregiver empowerment and self-care. It indicates that being aware of their adolescent's HIV status can motivate caregivers to take ownership of their adolescents' health, leading to improved adherence to medication and the adoption of healthy behaviors. This increased sense of responsibility can have long-term benefits for the overall well-being of the adolescent. These findings highlight the significant emotional, social, and health-related implications of HIV status disclosure on caregivers in the Katete District. By recognizing the initial emotional responses and fostering supportive family environments, caregivers can contribute to the resilience and overall well-being of adolescents following disclosure.

Chapter Five: Discussion Study Objectives

The outcomes observed in this study, which explored the experiences of caregivers following the disclosure of their adolescents' HIV status, provide valuable insights that resonate with the existing body of literature in several ways. While the specific focus of this study was on caregivers, the findings share common ground with previous research on HIV disclosure, caregiver dynamics, and the psychosocial impacts of HIV. This section aims to establish these connections and highlight the alignment of this study's findings with the broader literature.

Methods Employed by Caregivers in HIV Status Disclosure

This objective was covered in the study's discussion of the methods parents in Katete District used to tell their children about their HIV status. According to the literature analysis, three primary strategies—private conversations, family gatherings, and the use of visual aids—are employed by caregivers to inform adolescents about their HIV status. According to earlier research by Tucker et al. (2014) in Australia, Madiba and Mokgatle (2012) in South Africa, and Afolabi et al. (2017) in Nigeria, caregivers most frequently inform adolescents of their HIV status in private conversations [16,20]. According to findings from this study, with this approach, more private and personal talk is possible, and it can be beneficial to have a trusted adult there, like a therapist or healthcare professional.

Family gatherings can also be a useful setting for sharing HIV status, especially in societies where doing so is not the norm. By using this technique, the dialogue can become more commonplace and less intimidating for the adolescent. However, it's crucial to make sure that everyone in the family is in favor of the disclosure and that the adolescent is at ease discussing their HIV status. Adolescents and their families may benefit from increased knowledge and comprehension of HIV using visual aids. Posters, leaflets, and other educational materials might be used for this. The HIV diagnosis can be gently explained and questions from teenagers can be addressed with the help of visual aids. Additionally, according to this study's findings, caregivers ought to be urged to seek out expert counselling to assist them in getting ready for the disclosure procedure. Counselling can assist parents in gaining the knowledge and skills necessary to have a fruitful disclosure discussion with their child.

Overall, the data imply that there isn't a single, universal strategy for HIV status disclosure. Depending on the specific circumstances of the adolescent and their family, there may be more than one best disclosure approach. This research does, however, indicate that successful disclosure is mostly dependent on personalized communication, family involvement, and easily accessible information.

Barriers and Facilitators of HIV Disclosure to Adolescents

A key and recurrent topic in this analysis of caregiver interviews is the intense fear of discrimination and stigma that serves as a strong impediment to HIV disclosure. Parents and other adults have frequently expressed concern about the

negative social repercussions that their children would experience if the public learned of their HIV status. The critical necessity for comprehensive initiatives to fight discrimination and stigma within the community is highlighted by this persistent worry.

The worries of caregivers are consistent with more extensive research highlighting the negative effects of HIV/AIDS-related stigma [19]. A poignant reminder of the difficulty's caregivers confront is the dread of prejudice, social exclusion, and the possibility that adolescents would experience psychological distress because of stigma. The findings highlight the significance of creating a supportive community environment through community support networks and educational activities to overcome this obstacle. Such initiatives are necessary to foster an environment where disclosure can take place without the constant worry of social rejection, which will ultimately improve the well-being of teenagers.

Facilitators of Disclosure: Open and Supportive Family Dialogue

On the other hand, the study has highlighted open and encouraging family communication as a potent facilitator of the disclosure process. The crucial relevance of creating a safe environment for adolescents to express their feelings in the family was recognized by caregivers. Furthermore, it was thought crucial to have the continuous support of family members. The fact that teenagers with HIV are more likely to reveal their status, understand it, and accept it if their family supports them is recognized by caregivers.

These results are consistent with the literature already in existence that emphasizes the crucial part that family support plays in encouraging HIV/AIDS disclosure [17]. The creation of an atmosphere that encourages free communication not only builds trust but also forms the basis for adolescents' acceptance of their HIV status. It is within the family context that adolescents often find the emotional fortitude and resilience required to navigate the challenges associated with living with HIV.

Addressing Lack of Awareness and Comprehension: A Barrier Turned Facilitator

Another obstacle to disclosure that was discovered by this research is the community's ignorance of HIV. The disclosure procedure has been hampered by widespread misconceptions and preconceived assumptions regarding HIV. This highlights the critical requirement for thorough community education campaigns to overcome these myths. The creation of a setting where disclosure can happen without fear of retaliation requires a more comprehensive approach to raising public awareness and comprehension. Access to counseling services and support groups have also been identified as two key facilitators of the disclosure process by our findings. These materials were regarded by caregivers as priceless because they gave them direction, empathy, and a strong feeling of community as they navigated the difficult process of disclosing their adolescent's HIV diagnosis. These support systems' availability has been crucial in facilitating disclosure and giving caregivers the skills, they need to negotiate this difficult terrain.

This study highlights the complex interaction between facilitators and barriers in the disclosure of teenagers' HIV status. It is essential to launch a thorough campaign against stigma and discrimination to successfully remove these obstacles and improve the disclosure process. To create a setting where disclosure can take place with empathy, understanding, and acceptance, accessible counselling and support services, increased community awareness, and open family communication are essential first steps. These actions will ultimately improve the well-being of adolescents living with HIV.

Emotional, Social, and Health Outcomes of HIV Status Disclosure

This study's findings about the early emotional reactions of caregivers to HIV disclosure are in line with earlier research stressing the emotional difficulties brought on by such discoveries [23]. The astonishment, sadness, and perplexity shown by caregivers reflect the emotional upheaval frequently connected to getting a diagnosis of this kind [19]. These feelings reflect the seriousness of the situation and the requirement for a supporting setting. Importantly, the following development of resilience in caregivers is consistent with research showing the ability to grow and adapt psychologically in the face of difficulty [23]. These findings highlight the caregiver capacity for transformation and demonstrate how they might use these feelings as motivational resources.

Following disclosure, there was better family cohesion and communication, which is consistent with evidence highlighting the value of family-centered care in the treatment of HIV/AIDS [17]. To reduce the psychosocial effects of HIV/AIDS on adolescents, prior research has emphasized the critical importance of family support and open communication [16]. These claims are supported by this study's finding, which also provides insight into how transparency might spark fruitful family discussions. This resonance underlines the continuing value of family-centered care and the need to investigate new methods for fostering family dialogue following disclosure.

Studies stressing the significance of caregiver engagement in adolescents' healthcare are consistent with the empowerment of caregivers following disclosure [19]. The proactive attitude displayed by caregivers is in line with research that supports caregivers' active participation in medication adherence and healthcare decision-making [17]. This alignment draws attention to the transformative power of disclosure, which enables parents to act as health advocates for their children. It also emphasizes how crucial caregiver training and assistance are to maximizing their efficiency in this capacity.

Synthesizing the Themes and Literature

While the literature reviews primarily centered on the experiences of young people living with HIV, the themes emerging from this study align with and complement existing research. This synthesis underscores the interconnectedness of caregiver and adolescent experiences and highlights the broader implications for HIV/AIDS care and support. The emotional responses of both caregivers and adolescents following HIV disclosure represent a shared journey marked by initial shock, sadness, and confusion. While adolescents may initially grapple with the emotional impact of their diagnosis, caregivers similarly experience profound emotional reactions. These parallel emotional experiences underscore the deep emotional bond between caregivers and adolescents. This bond forms the foundation for ongoing support, understanding, and shared resilience.

The theme of enhanced family communication is a pivotal point of convergence in caregiver and adolescent experiences. Caregivers recognize the significance of open and supportive family dialogue as a means to foster understanding, acceptance, and a strong support system. Likewise, adolescents acknowledge the pivotal role of their families in their journey toward acceptance and well-being. This shared emphasis on family communication reinforces the interdependence of caregiver and adolescent experiences and highlights the crucial role of the family unit in the context of HIV/AIDS care. In this study, caregiver empowerment emerged as a significant theme, with caregivers taking on a more proactive role in managing the health and well-being of their adolescents. This empowerment extends beyond caregivers' individual experiences and directly impacts adolescents' lives. By assuming responsibility for medication adherence, promoting healthy behaviors, and fostering self-care, caregivers contribute to the long-term well-being of adolescents. This shared commitment to health and well-being reinforces the symbiotic relationship between caregivers and adolescents.

Understanding the interplay between caregiver and adolescent experiences has profound implications for HIV/AIDS care and support. Health professionals and caregivers must work collaboratively to provide comprehensive care that addresses the emotional, social, and health-related needs of both caregivers and adolescents. By recognizing the interconnectedness of these experiences, interventions can be tailored to foster resilience, enhance family communication, empower caregivers, and promote the overall well-being of adolescents living with HIV. This holistic approach is essential in ensuring the comprehensive care and support that adolescents and their caregivers require on their journey toward acceptance and well-being.

Chapter 6: Conclusion and Recommendations

Conclusion

The techniques used by caregivers to disclose their HIV status were evaluated in this study, along with the facilitators and impediments to disclosure, and the effects that revelation had on adolescents' emotional, social, and physical well-being in the Katete District. The results shed important light on the disclosure procedure and how it affected the lives of the young people who were affected. According to this study, caregivers employ a variety of techniques that are adapted to their unique situations and the demands of teenagers. These approaches place a strong emphasis on family involvement, open access to information, and expert advice. They open channels for candid communication, comprehension, and acceptance of teenagers' HIV status.

Fear of stigma and discrimination, as well as a lack of awareness and understanding in the community, are obstacles to disclosure, whereas open family communication, availability to counseling services, and participation in support groups have emerged as facilitators. Enhancing the disclosure process requires addressing stigma, encouraging open dialogue, increasing community awareness, and offering support services. Recognizing the alignment of this study's findings with the broader literature reinforces the importance of caregiver-focused interventions within the context of adolescent HIV/AIDS care. The emotional challenges and subsequent resilience demonstrated by caregivers underscore the need for targeted psychosocial support programs. The emphasis on improved family communication and caregiver empowerment validates the importance of holistic, family-centered care. Healthcare providers, educators, and policymakers must draw from these findings to develop strategies that acknowledge the integral role of caregivers in adolescents' health journeys. By aligning interventions with the experiences and needs of caregivers, we can enhance the overall quality of care provided to adolescents living with HIV.

Recommendations

Considering the findings of this study, several suggestions can be made to assist caregivers, youth, and communities in the HIV status disclosure process:

- **Strengthen Community Education Programs:** Local health authorities, NGOs, and educational institutions should collaborate to create and implement comprehensive community education initiatives aimed at combating HIV/AIDS stigma and discrimination. These initiatives should aim to promote truth, dispel myths and misconceptions, and cultivate a welcoming and inclusive society.
- **Provide Counseling Services and Support Groups:** Healthcare facilities and community organizations should work together to enhance caregivers' and adolescents' access to counseling services and support groups. These services should offer emotional support, guidance, and a platform for sharing experiences to help caregivers and teenagers navigate the challenges of disclosure.
- **Foster Open Family Communication:** Parenting support organizations, along with mental health professionals, should provide resources and training to encourage caregivers to cultivate honest and supportive family

communication. Additionally, these entities should work towards fostering a non-judgmental and empathetic family environment.

- **Develop Age-Appropriate Educational Materials:** Educational institutions, healthcare providers, and NGOs specializing in youth health should collaborate to create instructional resources tailored to different age groups. These resources should facilitate discussions about HIV/AIDS, disclosure, and self-care. They can assist parents in initiating conversations, addressing questions and concerns, and empowering teenagers to take charge of their health.
- **Establish Peer Support Networks:** Youth organizations, in collaboration with healthcare facilities and NGOs, should take the lead in establishing peer support groups for young people living with HIV. These networks can provide teenagers with a sense of community, alleviate feelings of loneliness, and promote social integration. Peer support can significantly enhance teenagers' emotional well-being and self-confidence.
- **Collaborate with Healthcare Professionals:** Local health authorities and healthcare institutions should encourage and facilitate collaboration between caregivers and medical professionals throughout the disclosure process. Healthcare professionals can offer guidance, accurate information, and specialized attention to the medical aspects of HIV/AIDS, providing comprehensive support for both parents and teenagers.

These recommendations are intended to create a supportive environment for teenagers and their caregivers during the HIV status disclosure process. By removing obstacles, enhancing support systems, and promoting open communication, caregivers and communities can improve the wellbeing and outcomes for young people in the Katete District who are living with HIV.

Recommendations for Further Study

The involvement of healthcare professionals should be studied further to understand how they may support parents and children of teenagers during the disclosure process [31-77]. A better understanding of the types of support and resources required to help caregivers initiate and manage disclosure can be gained by looking at the viewpoints and experiences of healthcare professionals including counselors, doctors, and social workers.

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Acknowledgements

I present my sincere appreciation and thanks firstly to the entire University of Zambia management, especially the School of Public Health for their support and guidance during the whole process. Secondly, great appreciation to my family, especially my wife (Miyanda N. Hamangaba) who has been so understanding and a source of encouragement during my busy schedule. My mother (Emily Nakaluli Hamweene) who have not lived to see my works but has been my inspirational in my educational journey. Further, I offer my gratitude and thanks to my supervisors Dr. Margarate N. Munakampe and Dr. Oliver Mweemba for their timely and dedicated guidance throughout the process. I would like to extend my appreciation to Dr. Alice Ngoma Hazemba and Dr. Hikabasa Halwindi for their exceptional coordination of the course. Their efforts in creating an engaging and enriching learning environment have been truly commendable.

Lastly, my sincerest gratitude to Claudius Makungu for his invaluable assistance throughout this research project. His expertise and guidance were crucial in ensuring the successful completion of this study. I am deeply appreciative of his time, effort, and patience in assisting me with the data collection, analysis, and interpretation. His willingness to share his knowledge and expertise has been instrumental. Once again, thank you Claudius for your unwavering support and dedication to this research.

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Appendices

Appendix 1: Information Sheet

The University of Zambia School of Medicine Department of Public Health

Disclosure of HIV/AIDS Status to Adolescents: Experiences of Care Givers in The Context of Culture Driven Setting in Katete District, Eastern Province, Zambia.

Information Sheet

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Background and Rationale for the Study

HIV disclosure to adolescents is crucial for promoting their physical, emotional, and psychological well-being. By sharing their HIV status with them, we empower them to take ownership of their health, make informed decisions, and develop resilience. Disclosure also fosters trust and open communication between caregivers and adolescents, helping to alleviate stigma and anxiety. Moreover, it enables adolescents to access appropriate support, treatment, and resources, ensuring they can thrive and reach their full potential. By disclosing their HIV status, we prioritize their autonomy, dignity, and future.

Purpose

This study added to the body of information and research on Zambian Guardians' disclosure of HIV status to adolescents. The motivations and experiences of Guardians who disclosed or did not disclose the HIV status to teenagers were discussed, as well as cultural attitudes and customs that affected the decision and method of disclosure. This study also emphasized the difficulties and opportunities that Guardians had when telling teenagers, they had HIV, as well as how they handled the emotional, social, and practical repercussions of disclosure. Healthcare professionals, policymakers, and other stakeholders who were involved in the care and support of teenagers living with HIV and their Guardians should benefit from the study's findings.

Procedures

In-depth interviews with the participants was one of the data-gathering techniques used in this qualitative study. A semi-structured interview guide served as the direction for the interviews. The interview guide included open-ended

questions and prompts that were intended to delve into the experiences, viewpoints, and feelings of Katete District caregivers of HIV-positive adolescents about the disclosure and non-disclosure of their status.

Who Will Participate in the Study?

Guardians, and parents, of teenagers in Zambia's eastern region of Katete were the study's target demographic. These were the individuals who qualified to be the investigation's focus and could offer rich, pertinent information about their experiences disclosing and not disclosing their HIV status to teenagers living with HIV.

Cost

All the possible costs to be met solely by the principal investigator.

Compensation for Participation in the Study

There will be no form of physical compensation of the participants of the study as it does not involve any bodily injuries or exposed to harmful substances.

Reimbursement

No reimbursement to be done as participants will be followed and interviewed from their own homes or places they can be comfortable to discuss such a topic.

Confidentiality and Voluntary statement

Your participation in this study is voluntary and confidential. All information collected during this study will be kept confidential and anonymous to the fullest extent possible. Your name and any identifying information will not be linked to the data or results. I am committed to protecting your privacy and maintaining the confidentiality of your responses. Information will be stored securely and only accessed by authorized research personnel. Please note that aggregate results may be shared in publications or presentations, but these will not include any information that could identify you personally. If you have any questions or concerns, please do not hesitate to ask. The interviewer has discussed this information with me and offered to answer my questions. For any further questions, I may contact the Chairperson, Unzabrec on the following details

NAME: Sody Mweetwa Munsaka, BSc., MSc., PhD Chairperson
Tel: +260977925304.

Appendix 2: Statement of Consent

..... has described to me what is going to be done, the risks, the benefits involved and my rights regarding this study. I understand that my decision to participate in this study will not alter my usual medical care. In the use of this information, my identity will be concealed. I am aware that I may withdraw at any time. I understand that by signing this form, I do not waive any of my legal rights but merely indicate that I have been informed about the research study in which I am voluntarily agreeing to participate. A copy of this form will be provided to me.

Name:.....Signature of participantAge..... Date (DD/MM/YY)

If you have any further questions, please contact the University of Zambia Biomedical Research Ethics Committee.

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Federal Assurance No. FWA00000338 IRB00001131 of IORG0000774 NHRAR- REC No 2021-05-0002.

Appendix 3: Interview Guide

Interview Guide: HIV Status Disclosure to Adolescents.

Introduction

Thank you for agreeing to participate in this interview. The purpose of this study is to explore the experiences and perspectives of caregivers regarding HIV status disclosure to adolescents in the Katete District. Your insights will contribute to a better understanding of the methods, barriers, facilitators, and outcomes associated with disclosure. Please note that your participation is voluntary, and all information provided will be kept confidential. With your consent, the interview will be audio-recorded for accurate data collection. Do you have any questions before we begin?

Personal Background

- Can you please provide some information about yourself, such as your age, gender, and relationship with the adolescent you are caring for?

Methods Employed in HIV Status Disclosure

- How did you disclose the HIV status to the adolescent? Could you describe the method or approach you used?

- Why did you choose this particular method? What factors influenced your decision?
- How did you create a safe and comfortable environment for the disclosure?
- Did you consider the individual needs and circumstances of the adolescent when deciding on the method of disclosure? If so, how?

Barriers to HIV/AIDS Disclosure

- Were there any barriers or challenges that you encountered during the disclosure process? If yes, could you please describe them?
- Did you have any concerns about stigma or discrimination that the adolescent might face if their HIV status was known? How did this influence your decision to disclose or not disclose their status?
- How did you address these barriers or concerns? Were there any strategies or actions you took to overcome them?

Facilitators of HIV/AIDS Disclosure

- Were there any factors or circumstances that facilitated the disclosure process? If yes, could you please explain them?
- Did open and supportive family communication play a role in the disclosure? How did you create a safe space for the adolescent to express their thoughts and emotions?
- Did you seek any external support or guidance during the disclosure process? If yes, how did it contribute to facilitating the disclosure?

Emotional, Social, and Health Outcomes

- How did the adolescent initially respond emotionally upon learning their HIV status? Could you describe their immediate reactions?
- Did you observe any changes in the adolescent's emotional well-being over time following the disclosure? If yes, what were those changes?
- How did the disclosure impact family communication and relationships within the family unit?
- Did the disclosure influence the adolescent's health-related behaviours, such as adherence to medication or adoption of healthy habits? If yes, how?

Reflections and Lessons Learned

- Looking back at the disclosure process, what do you consider the most significant lesson or insight you gained?
- Is there anything you would have done differently during the disclosure? If yes, what would that be?
- Based on your experience, what advice or suggestions would you give to other caregivers who are preparing to disclose HIV status to their adolescents?

Conclusion

Thank you for sharing your experiences and insights. Your participation in this study is greatly appreciated. Please note that the information provided will be kept confidential. If you have any additional comments or thoughts you would like to share, please feel free to do so.