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Perspectives of Girls, Families, and Healthcare Workers on Accessing Services for Adolescents with Perinatal HIV in Nigeria

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Walden University
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Abstract

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MPH, Walden University, 2014

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Dissertation Submitted in Partial Fulfillment

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Abstract

Adolescents living with Human Immunodeficiency Virus (HIV) include those who were infected from their mother perinatally (PHIV) and those who were infected through sexual behaviors or drug use. Nigeria contributes the largest burden of children born with HIV globally, due to poor implementation of its prevention of mother-to-child transmission program. With advances in antiretroviral therapy (ART), more children and adolescents with HIV survive into adulthood. However, there are challenges to ART including access, uptake, adherence, and risks of long-term exposure. Using the social ecological model and a phenomenological approach, this qualitative study was designed to understand the experiences of adolescent Nigerian girls aged 15-19 years with PHIV, and their caregivers and health workers with respect to providing support. Interviews with three adolescent girls with PHIV, three caregivers, and three healthcare workers were conducted and analyzed. Findings indicated factors that hinder access to services and adherence to ART include low comprehensive HIV knowledge, HIV-related stigma, disclosure challenges, lack of transport fare to facility, and pills fatigue. Factors that strengthen access to services and adherence to ART include resilience of the girls, free and friendly family-centered healthcare services, the mother-child bond (both live with HIV), and support group meetings. Findings also show a decline in adverse drug reactions from antiretroviral drugs among these girls as the facility innovatively prevent and/or adequately manage these reactions. These findings highlight the implications for social change: improved quality of life for and optimal ways to support adolescent girls with PHIV in Nigeria.

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Dedication

This study is dedicated to the Almighty God who impressed it upon my heart to embark on this remarkable Ph.D. journey and for giving me the support and grace to finish strong.

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Lastly, I am grateful to the Hospital Coordinator, ART Coordinator and all the staff of the HIV/AIDS Unit of the Health facility where I conducted my research work and all the research participants who are now my good friends.

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Chapter 1: Introduction to the Study

Background

Despite increasing intervention to address the spread of Human Immunodeficiency Virus (HIV) globally across the different age groups, mortality among adolescents aged 10-19 years is still on the rise with about 1.8 million adolescents in this age bracket living with HIV globally (Galea et al., 2018). In sub-Saharan Africa, where more than 80% of adolescents living with HIV reside, AIDS is the leading cause of death (Dulli et al., 2018; Galea et al., 2018) with females aged 15-24 years having high incidence rate (Toska et al., 2017) due in part to a risky lifestyle including unprotected sex injectable drug use, as well as use of other drug types (WHO, 2005).

In Nigeria, with an estimated HIV population of 1.9 million, HIV prevalence was 150/100,000 among 15-49 years, and 20/100,000 among children 0-14 years, according to the Nigeria HIV/AIDS Indicator and Impact Survey (NAIIS; UNAIDS, 2019). More females aged 15-24 years are infected with HIV, with prevalence of 1.9%, compared to men, with the prevalence of 0.9% (NACA, 2019). Prior to the NAIIS report, the National Agency for the Control of AIDS (NACA) in Nigeria had indicated HIV prevalence of 420/100,000 for adolescents aged 15-24 years and estimates the number of adolescents living with AIDS is 160,000 for 10-19 years old (NACA, 2016). The improvement in prevalence has been attributed to better surveillance systems in the country; however, there are challenges as interventions designed to improve health outcomes among adolescents living with HIV are often hampered by limited knowledge about HIV, stigma and discrimination, fear of disclosure, and lack of social support coupled with the psychological, social, and physical changes associated with adolescence (Dulli et al., 2018).

Since the first AIDS case was reported in Nigeria in 1986 (NACA, 2014), Nigeria faces a generation of children who were infected with the HIV virus through mother-to-child transmission (MTCT). Although some of these children could not live beyond infancy, those who did have, over the years, grown into adolescence and young adults and are currently visiting health facilities for treatment and are in long term care. This can be attributed to the advent and availability of antiretroviral therapy (ART) which has created the opportunity for more children and adolescents living with HIV infection to have their lives prolonged, and are able to transition into adulthood (Adejumo et al., 2015b; Galea et al., 2018). ART has been regarded widely as most successful in treating the HIV disease, reducing it from chronic to a manageable illness (Galea et al., 2018; Inzaule et al., 2016). Optimal adherence to ART has been shown to drastically reduce morbidity and mortality that are related with AIDS (Martelli et al., 2019) by improving viral suppression (Natukunda et al., 2019). Improving viral suppression also lowers the risk of transmitting the virus to others (Natukunda et al., 2019). This is referred to as secondary HIV prevention: implementing prevention activities such as adherence to ART to achieve HIV viral load suppression for healthier and longer life, and to prevent transmission to those who are HIV negative (U.S. Department of Veterans Affairs, 2018). Supporting adherence to ART for adolescents who are HIV positive, especially for adolescents who may be sexually active, is the most effective means of preventing HIV transmission. However, there are challenges associated with access, uptake, and adherence, as well as long term exposure of ART among these adolescents which is cause for concern and was thus explored and addressed in this study (see Comley-White et al., 2019).

Research Problem

Adolescents living with HIV (ALHIV) are known to experience suboptimal access and outcomes of care resulting in poorer rates of treatment adherence, disclosure, viral suppression, and long-term immunologic recovery (Toth et al., 2018). Perinatal HIV (PHIV) infection or vertical transmission refers to the transmission of HIV to infants and children from their mother during pregnancy, labor and delivery, and breastfeeding (CDC, 2019). Vertical transmission has been attributed to gaps in HIV testing which have allowed pregnant HIV positive mothers to go untreated thereby spreading the disease to their children (Cohen, 2018). Nigeria is known to contribute the largest burden of babies born with HIV globally; in 2016, 21.58% of HIV positive pregnant women from the country transmitted the disease to their children (Cohen, 2018). AIDS related death have also increased among adolescents owing to a generation of HIV perinatally-infected children who are growing into adolescents (UNICEF, 2018). With the availability of ART, the disease can be managed, and infants and children can survive into adolescence and adulthood if they adequately adhere to their medication (Tshuma, 2015). However, adolescents who are placed in long-term care (Aurpibul et al., 2016) often have to take responsibility for managing their own health and continuum of care (Dahourou et al., 2017). However, this comes with numerous challenges, both clinical (e.g., availability of drugs, adherence to medications), and social (e.g. in relation to family and community; Galea et al., 2018).

The clinical challenges faced by young girls and women with HIV, and the impact of HIV prevention, treatment, and care, have been well researched in the United States (Folayan et al., 2015) and Sub-Saharan Africa. In Nigeria, however, despite the significant contribution of PHIV to the incidence of HIV among children and adolescents, there has been very little research on the experience and effects of long-term exposure to HIV and long-term ART, and none on the experience of girls with PHIV (Mbachi, 2018). This highlights the gap in literature that this study addressed. Overall, there are insufficient data on the challenges experienced by adolescent girls living with PHIV, especially in low resource countries plagued with poorer health care access, poverty, and a high HIV burden (Comley-White et al., 2019), such as Nigeria. Understanding the challenges experienced by adolescent girls with PHIV, and the impact of long-term exposure to HIV and ART. can provide a basis for the development of an appropriate model of care for adolescents with PHIV. Findings from my study address barriers such as social stigma, discrimination and other social factors that affect physical and mental health, which affects uptake of and adherence to ART (see Winskell et al., 2016).

Purpose Statement

The purpose of the study was to understand the challenges adolescent girls, aged 15-19 years, living with PHIV face accessing services and adhering to medication. The study sought to understand the impact of long-term exposure to HIV and ART by adolescents with PHIV (Comley-White et al., 2019) and to understand the barriers and facilitators of such barriers that could hinder or have hindered adherence and access to ART (Galea et al., 2018). Addressing these challenges can provide opportunities for adolescent girls with PHIV to live healthier, longer lives and ultimately reduce the risk of sexual transmission of HIV.

Significance

The results of the study provide insights for the development of context specific interventions to improve service uptake at health facilities, and improve adherence to ART, which could lead to viral suppression among adolescent girls 15-19 years living with HIV in the Federal Capital Territory, Nigeria. Findings addressed barriers to uptake and adherence to ART such as social stigma, discrimination, and other social factors that affect physical and mental health, which affects uptake of and adherence to ART (Winskell et al., 2016). This study can contribute to social change by contributing to policy formulation, improve current intervention frameworks and project designs, and address major challenges identified with long term exposure to ART by adolescents living with PHIV.

By bringing to the fore the lived experiences of adolescent girls living with HIV, the study contributes to positive social change by highlighting the sociodevelopmental needs of adolescents living with HIV and how to address them to meet their future aspirations, contribute to economic development, and realize their sexual and reproductive rights (see Folayan et al., 2014). Positive social change is fostered when healthcare workers have the capacity to provide adolescent friendly services and strengthen adolescent support groups which provides the platform for social cohesion and psychosocial support and promotes medication adherence.

Theoretical Framework

The theoretical framework for the study was the Urie Bronfenbrenner's (1970) social ecological systems theory which provides insights on human development by placing the individual in a ring encircled by various systems (Kilanowski, 2017). This makes it possible for the social analysis of the different layers or constructs of the model to be conducted (Galea et al., 2018). In relation to health, this theory states that a disease at an individual level results from a joint interaction between the individual and the environment at various levels which includes family, friends, social networks, communities, and culture (Galea et al., 2018). The social ecological model (SEM) aligned and supported the purpose of the research, the research questions and the choice of design (see Grant & Osanloo, 2014); the lived experiences of adolescent girls with PHIV using the SEM was viewed from their personal experiences of living with PHIV infection and included their parents/guardian (family) as the primary caregiver and healthcare workers who provide HIV services to them at a health facility. Examining these various levels of participants within their context provided better understanding of the experience of adolescent girls living with PHIV with respect to access to services and adherence to ART.

Research Questions

The study aimed to answer the following research questions.

Research Question 1 (RQ1): What is the lived experience of Nigerian girls living with PHIV regarding personal, family, and social challenges in accessing health services and adhering to ART?

Research Question 2 (RQ2): What is the lived experience of family members of Nigerian girls with PHIV regarding access to health services and adherence to ART?

Research Question 3 (RQ3): What is the lived experience of healthcare workers regarding Nigerian girls' access to health services and adherence to ART?

Research Question 4 (RQ4): What are the perceptions of Nigerian girls with PHIV, their family members, and healthcare workers regarding how HIV services for adolescent girls could be improved?

Nature of the Study

The study involved a qualitative research method which employed the use of the SEM theory. Qualitative studies depend on text and image data generated and consist of unique steps in data analysis that draw on diverse designs (Creswell, 2014). This is consistent with the phenomenological research approach which tends to provide an understanding and in-depth description of a phenomenon from the individual lived experience of the phenomenon (Yuksel & Yildirim, 2015). Examining these various levels of participants' experiences through the collection of primary data within their context provided better understanding of the experience of these adolescent girls living with PHIV with respect to access to services and adherence to ART.

Types and Sources of Data

Interviews were conducted separately with adolescent girls living with PHIV, their primary caregiver (parent/guardian), and healthcare workers.

Limitations, Challenges, and/or Barriers

The limitations of the study includes the fact that all the adolescents who participated in the study were female which limits the study outcomes to their experience of living with perinatal HIV when compared to the inclusion of the male gender in the same health facility. The study was conducted in a faith-based health facility which does not provide other adolescent services such as sexual reproductive health because of their beliefs. There might be some limitations on the accuracy and validity of my findings because I collected and carried out the analysis alone manually with some advice from my Chair although I maintained impartiality during the rigorous analysis of the data.

Because purposive sampling was used in the study only the perspectives of a few adolescent girls who volunteered to share their experiences was reported and not all adolescent girls with PHIV and receiving HIV services in the health facility. Thus, the study outcomes cannot be generalized as the experience of all other adolescent girls with PHIV receiving HIV services in the same health facility.

There was the need to engage the service of a professional counselor from the health facility to provide psychosocial service to any research participants who needed such service.

Definition of Key Concepts

Adolescence: The Encyclopedia Britannica (2019) defines adolescence as the "transitional phase of growth and development between childhood and adulthood". However, the World Health Organization (WHO, 2019) identifies adolescents as persons between the ages of 10 and 19 years and may refer these as young persons between the ages of 10 and 24 years. For the purpose of this study, adolescence range from 10 to 19 years and the actual range for the study sample is 15-19 years.

HIV: This is the human immunodeficiency virus, which attacks the body's immune system, especially the CD4 cells, also known as T cells responsible, which help the immune system fight off infection (CDC, 2019). If untreated, the HIV reduces the number of the CD4 cells in the body, making it susceptible to other infections and diseases leading to Acquired Immune Deficiency Syndrome (AIDS; CDC, 2019)

AIDS: The Acquired Immune Deficiency Syndrome is the most severe stage of HIV infection characterized by badly damaged immune system with increasing number of severe illnesses identified as opportunistic infections (CDC, 2019). Symptoms of AIDS include sweats, fever, chills, swollen lymph glands, weakness, and weight loss. People with AIDS often have high viral load and typically survive about 3 years (CDC, 2019).

ART: Antiretroviral therapy is a combination of three or more antiretroviral (ARV) drugs designed to stop the progression of the HIV by suppressing the HIV virus (WHO, 2020) and reducing the amount of the virus in the blood and body fluids (CDC, 2019). If taken as prescribed by a healthcare provider, ART reduces the transmission of the virus to others (CDC, 2019). It is recommended to all persons living with HIV irrespective of how long they have had the virus or healthy they may appear (CDC, 2019).

Adherence to ART: Adherence describes patients' behavior towards taking prescribed drugs correctly based on mutual agreement between the patient and the healthcare provider (Federal Ministry of Health, 2020). It involves four principles: taking the right drugs, the right dose, the right frequency, and at the right time (Federal Ministry of Health, 2020). In many studies, adherence to ARV is measured by expressing the number of doses taken by a person living with HIV (PLHIV) as a percentage of the number of doses prescribed (Federal Ministry of Health, 2020). Hence, a pill count process is initiated to achieve this; for every clinic visit, a PLHIV is asked to bring back the drug stock or the PLHIV counts the drug stock at home before each clinic visit. The total number of tablets for each of the drug stock and the number are recorded (Fong, 2019). Adherence to ART of at least 95% which indicates high or optimal adherence, is needed for successful treatment outcomes such as improved virology, immunology, and clinical outcomes (Akahara et al., 2017; Federal Ministry of Health, 2020) among people living with HIV.

Access to health services: Access to health describes the use of personal health services to achieve the best health outcomes in a timely manner (Healthy People, 2020). There are three distinct steps involved which includes: gaining entry into the health care system, accessing a location where needed health care services are provided (geographic availability), and finding a health care provider whom the patient trusts and can communicate with (personal relationship; Healthy People, 2020).

Summary

This chapter provided a brief background on HIV globally, in Sub-Saharan Africa and in Nigeria specifically. With the availability of ART in poor resource country such as Nigeria, many HIV infected children have successfully grown into adolescents and have their viral load suppressed. This chapter provided a brief understanding of the research problem highlighting challenges with access to HIV services, disclosure, adherence to medication, among others experienced by adolescent girls living with PHIV. It also highlights the paucity of research on long-term exposure to HIV and ART, the research questions, and the use of the SEM in the context of phenomenology as the theoretical framework to understand the personal experiences of adolescent Nigerian girls aged 15-19 years living with PHIV in accessing services and adhering to medication across family and health facilities. The chapter also discussed the purpose and significance of the study. Chapter 2 presents the literature review for the study with reference to the lived experience of ALHIV. It will also discuss in detail, the SEM as the theoretical framework to guide the study.

Chapter 2: Literature Review

Introduction

This chapter describes PHIV and behavioral HIV (BHIV) infection among adolescent girls in detail. Although a global challenge, PHIV infection has been addressed with favorable outcomes in different countries in Sub-Saharan Africa, but some regions are still having some challenges as some children are still born with HIV infection in countries with poor access to ART, suboptimal adherence, and inadequate health systems. Worthy of note is the fact that ART has succeeded in reducing the mortality of HIV in adolescents to a chronic disease, thus reducing mortality resulting from HIV/AIDS among this age group (Adejumo et al., 2015a; Galea et al., 2018). This chapter examines the prevalence of PHIV in Sub-Saharan Africa, as well as Nigeria. It also discusses the role of healthcare workers to adolescent girls living with PHIV and BHIV.

Also, challenges faced by adolescent girls living with PHIV and BHIV are discussed through the lens of the SEM. The SEM recognizes the fact that individual health is influenced by factors within the individual and the environment. The chapter discusses PHIV and BHIV in adolescent girls with their personal experience and environmental circumstances that invariably affects them. The SEM guided me in exploring the experience of these girls living with HIV and on long term exposure to ART, and to better understand the various challenges they face relating to their families, communities, society, and health facilities where they receive treatment.

Literature Search Strategy

The literature searched and reviewed covered the period from 2014 to 2021 and includes theories and models that support the theoretical framework of the research. Databases engaged in the literature search include Scholar Google, EBSCO, and CINAHL Plus. Search terms used were in combination form and included *Adolescent girls with perinatal HIV in Nigeria, Social-Ecological model and HIV, Social-Ecological model and adolescents living with HIV in Nigeria, Perinatal HIV infection among adolescent girls in Nigeria, Social-Ecological model, vertical HIV infection,* and *Behavioral HIV*.

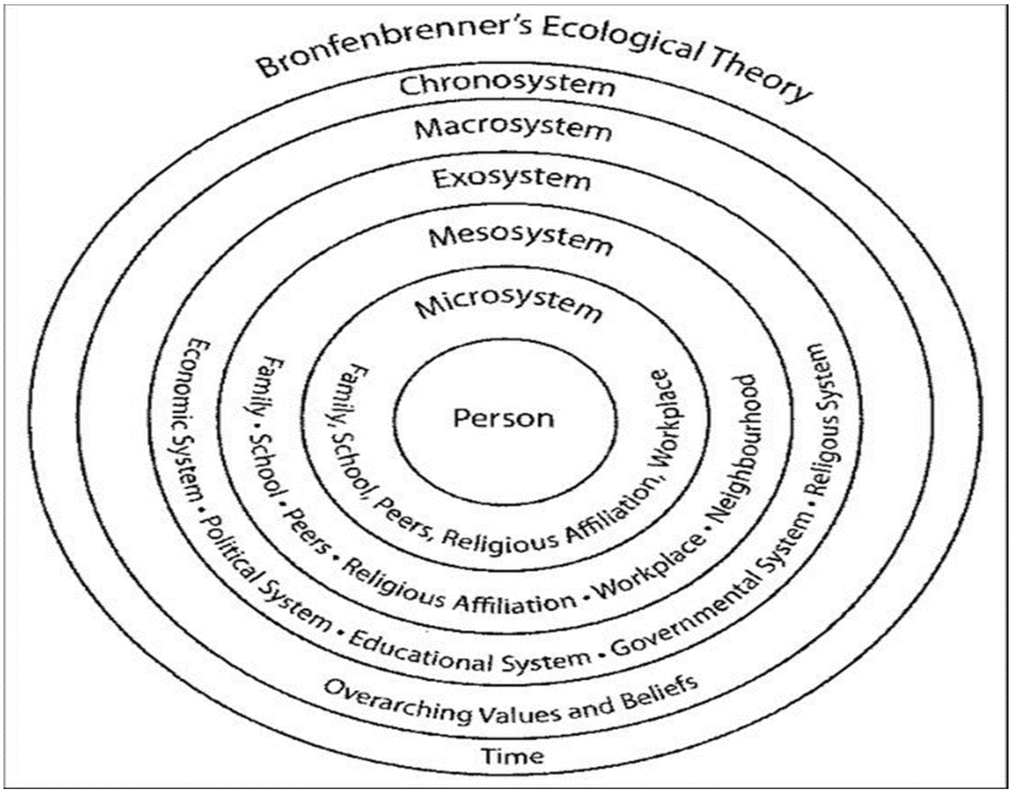
Theoretical Framework: Social Ecological Model (SEM)

I utilized the SEM as the theoretical framework for this study. The introduction and application of ecology to human behavior provided by Bronfenbrenner's ecological model (1979) describes the relationship between a person and the environment, including the physical and social characteristics at five systemic levels: the microsystem, mesosystem, the exosystem, macrosystem (Dumont, 2009) and the chronosystem (Harkonen, 2007: Johnson, 2008).

The microsystem depicts the experiences and behavior derived from interpersonal relationship when one associates with their immediate environment (Bronfenbrenner, 1994). The immediate environment includes one's family, place of work, school, peers and religious affiliations, and the more a person interacts with any element of their immediate environment, the more influence that element exerts on the person (see Figure 1; Bronfenbrenner, 1994). With reference to my study, the microsystem for adolescents living with PHIV and BHIV includes social network of relationships with the family, friends, schools, and clinics where they receive treatment (Jena, 2014). The more nurturing and encouraging the social networks are to the ALHIV, the more encouraged they are to make informed decision about disclosing their HIV status (Mpofu & Jacobs, 2017).

Figure 1

Bronfenbrenner's Ecological Theory



Note. Adapted from "Moving "Eco" Back into Socio-Ecological Models: A Proposal to Reorient Ecological Literacy into Human Developmental Models and School Systems," by N. Stanger, 2011, *Human Ecology Review, 18*(2), P. 169 (https://www.researchgate.net/publication/285232380_Moving_eco_back_into_socio-ecological_models_A_proposal_to_reorient_ecological_literacy_into_human_developmental_models_and_school_systems).

The mesosystem describes many possible relationships that may exist between any elements of two microsystems as revealed by Bronfenbrenner (1994). An example may include relationships between home and school, classmates and school, and place of work and friends (Bronfenbrenner, 1997). The mesosystem for adolescents living with PHIV and BHIV will include the interaction between them and their caregivers or guardians, other family members, the clinics where they receive treatment, their friends, and schools. These relationships are very important to adolescents as it confers social identity and role definition to them (Marcia, 1968; Jena, 2014). This domain reveals a bidirectional influence among the elements as ALHIV (PHIV and BHIV) are influenced by the attitude of caregivers or family members about HIV as well as their own attitude about HIV (Jena, 2014). Thus, the positive or negative lived experiences of ALHIV is influenced by the level of richness of the communication between them and their caregivers or parents and other elements within the system such as the health care providers (Jena, 2014; Mburu et al., 2014; Stein et al., 2014). The overall attitude of family and health care workers impacts on the level of adherence to ART and in overall, the management of their health.

The exosystem comprises the formal and informal relationships between two or more settings that involve the developing person being present and the other where the developing person is not present, but events that occur in such settings indirectly influence the processes within this setting (Bronfenbrenner, 1979, 1994). Thus, the developing person is not an active participant in any of the settings. With reference to

ALHIV, the exosystem includes the networks of caregivers or guardians, other family members such as siblings and friends, and the measure to which the adolescent's HIV status impacts these networks (Jena, 2014). The ALHIV is a nonactive participant; however, events that occur in some settings affect the setting housing the ALHIV (Jena, 2014). The domain also contains policies and informal structures that may affect treatment, care, and support services for ALHIV and their caregivers (Jena, 2014).

The macrosystem showcases trends in the three domains of micro, meso and exosystems as they relate to belief systems, material resources, customs, bodies of knowledge, and lifestyles embedded in these systems (Bronfenbrenner, 1997). It considers the specific social and psychological features in the macrosystem that affects the conditions and processes taking place in the microsystem (Bronfenbrenner, 1997). For example, some harmful cultural practices such as female genital mutilation (FGM) are known to increase the risk of HIV transmission among adolescent girls in Nigeria (Udeh et al., 2016). These practices are justified in the name of culture and traditions (Udeh et al., 2016).

The fifth system is the chronosystem developed from the life experiences of a person and may affect the entire ecosystem (Harkonen, 2007: Johnson, 2008). It describes the change or consistency over time that affects the environment where a person lives as well as the characteristics of the person (Bronfenbrenner, 1997). For example, the family history of an adolescent girl living with PHIV may include the death of family members due to HIV related illnesses (Mpofu, 2015; Mpofu & Jacobs, 2017). This may affect the adolescent along the different levels of the ecosystem and may include lack of financial support from the immediate family, community, or they may be faced with stigma and discrimination from health facility staff.

Social ecology has been used to establish the link and interplay between the health of young people especially adolescents living with HIV and the environment they live in (Galea et al., 2018; Mburu et al., 2014). For example, Mburu et al. (2014) mapped out the determinants of adolescent health using the individual, family, community, and socio-physical environment constructs of the social-ecological model. Assets identified across the different constructs include personal competence (individual), relationship of adolescents with parents and peers (family), schools within neighborhood (community) (Mburu et al., 2014). Similarly, Inzuale et al. (2016) identified social level factors using SEM when assessing barriers to ART adherence among adolescents living with HIV as challenges in disclosing HIV status to perinatally infected children growing into adolescence due to fear of negative reaction, fear of being blamed for the infection or fear of inability of the infected children to comprehend the severity of their health condition, and the absence of a supportive mechanism to assist parents or caregivers with disclosure. As an important source of adherence support, the role of family cannot be overemphasized (Mburu et al., 2014), as adherence behavior or support mechanism of adolescents provided by caregivers (parents or guardians), were reported to have been negatively impacted by the absence of food support, medication reminders, transport support and escort to treatment sites during clinic days (Inzaule et al., 2016).

For health system related factors that affect ALHIV, stigma and discrimination were reported as being common in some clinics in Zambia (Mburu et al., 2014). Other factors included long waiting hours at health facilities, insufficient care and attention by health care workers, staff attrition, gradual phase out of adolescent support groups which serve as platform for social networking, and insufficient drugs for treatment of opportunistic infection (Inzaule et al., 2016).

This study sought to explore the experiences of adolescent girls living with PHIV at the individual, family and healthcare levels using the social ecological model as an analytical lens. The Social Ecological model is appropriate for this study as it supports the application of the phenomenological approach and provides a wider understanding of the experiences of adolescent girls living with PHIV and create opportunity for interventions that addresses their personal and family circumstances as well as strengthen service delivery. Understanding their individual and family experiences as adolescent girls living with PHIV provides the unique opportunity of addressing challenges that may impede access to HIV services and adherence to ART.

HIV/AIDS Prevalence

United States

In the United States, approximately 1.1 million people age 13 years and above were living with HIV in 2016 while 38,739 persons were newly infected with the virus in 2017 (U.S Department of Health and Human Services, 2019). By age group, HIV incidence among 13-24 and 45-54 years decreased between 2010-2016 while increase was noticed for persons between age 25-34 years (U.S Department of Health and Human Services, 2019). By sex within the same year range of 2010-2016, HIV incidence decreased among females but remained stable among males in the United States (U.S

Department of Health and Human Services, 2019). About 41% of new HIV Infection found in 2017 was among adolescents and young persons aged 13-29 years (CDC, 2017) while those of age 13-24 years accounted for 21% of the new HIV infection in the same year (CDC, 2020). Adolescents aged 13-24 years are least likely to be tested for HIV, receive HIV treatment or have their viral load suppressed (CDC, 2020). About 36.3 million persons have died of AIDS-related illnesses since the epidemic started to 2020 (UNAIDS, 2021).

The main drivers of HIV incidence in the United States are men who have sex with men (MSM) across all races and ethnicity followed by heterosexual African American Women (CDC, 2016). Among young people, stigma has remained a major barrier to HIV prevention, HIV testing, and linked to low testing rates and poor adherence to treatment (White et al., 2015).

Sub-Saharan Africa

Although Sub-Saharan Africa accounts for about 12% of the world's population, it has a remarkable high HIV burden of 71% when compared to the global HIV burden in 2013 (Kharsany & Karim, 2016).However, 25. 6 million persons lived with the virus in the region in 2015 with women and children being mostly affected (Amuche et al., 2017). The adult HIV prevalence rate in Eastern and Southern Africa was 7.1% while Western and Central Africa had 2.2% adult HIV prevalence rate in 2015 (Amuche et al., 2017). According to current data, Africa region remains the most severely affected by HIV/AIDS with East and Southern Africa being the most affected with 20.6 million PLHIV and 670,000 new HIV infections in 2020 (UNAIDS, 2021). Populations at high risk of contracting HIV in the region are commercial sex workers, people who inject drugs, and men who have sex with men whose HIV prevalence is three times higher than men who have sex with women (Kharsany & Karim, 2016).

Compared to global data, AIDS related deaths are highest in Sub-Sahara Africa with West and Central Africa having less HIV prevalence but with more AIDS-related deaths due to challenges with providing ART to those in need of treatment (Robertson & Toole, 2019). About 310,000 persons were reported to have died of AIDS-related illnesses in East and South Africa in 2018 although this shows a 44% drop in the number of deaths since 2010 (UNAIDS, 2019). Children living with the virus are highest in Sub-Saharan Africa while women are reported to be disproportionately affected by HIV infection (Kharsany & Karim, 2016). New HIV infection among adolescents and young persons age 15-24 years far exceeds that of children in West and Central Africa mostly due to unprotected sex (Robertson & Toole, 2019).

With the introduction and widespread scale up of ART and concerted efforts of key stakeholders, there was a substantial decline in new HIV infections and AIDS-related deaths by 64% since the peak in 2004 and by 47% since 2010 (UNAIDS, 2021). In 2020, an estimated 680,000 PLHIV died globally from AIDS-related illnesses as compared to 1.9 million PLHIV in 2004 and 1.3 million PLHIV in 2010; there was 53% decline in AIDS-related illnesses among women and girls and 41% decline among men and boys since 2010. (UNAIDS, 2021). In the region, HIV is mostly transmitted through heterosexual sex while most children with the virus have been infected through vertical transmission (Kharsany & Karim, 2016).

Nigeria

The Nigeria National HIV/AIDS Indicator and Impact Survey (NAIIS) conducted in 2018 shows that HIV prevalence in Nigeria is 1.5% among 15-49 years, and 0.2% for 0-14 years children and further indicated that there are 1.9 million people living with the virus in the country (UNAIDS, 2019). HIV incidence is about 0.65% among all age groups accounting for 130,000 people with new HIV infection as compared to 120,000 recorded from 2010 (UNAIDS, 2019). AIDS-related deaths decreased from 72,000 to 53,000 from 2010 to 2018 (UNAIDS, 2019).

The implementation of the UNAIDS 95-95-95 strategy in Nigeria which envisioned that 95% of people living with the HIV virus should know their status, 95% of those who know their status should be linked to and access treatment while 95% of those accessing treatment should have their viral load suppressed, provides an understanding of the country's epidemic and gaps to be addressed (UNAIDS, 2019). In 2018, the UNAIDS strategy indicated that 67% of PLHIV knew their HIV status, 53% of people who knew their HIV status accessed treatment while 42% of PLHIV who were on treatment had their viral load suppressed (UNAIDS, 2019). It further revealed that 35% of children 0-14 years living with the virus were accessing treatment while 55% of PLHIV aged 15 years and above were on treatment (UNAIDS, 2019).

Prevalence of HIV Among Nigerian Women

As with other countries in Sub-Saharan Africa, women are disproportionally affected by the HIV epidemic in Nigeria accounting for 1,000,000 women out of 1,800,000 adults living with HIV; more women aged 15-24 years were newly infected with HIV than men (UNAIDS, 2019). This can be attributed to gender inequality fueled by culture and law (UNAIDS, 2016). Hence, the imbalance in gender which predisposes women to risk of HIV, favors men than women as the women do not decide on the use of contraception, their own healthcare and the number or spacing of their children (USAID, 2014) as they experience unequal access to HIV services, information and resources (International Council of AIDS Service Organization, 2007). This may be due to the society's perception of men as being sexually and economically superior to women which is further strengthened by some practices and institutions in the society such as female genital mutilation, marriage, polygamy among others (Klaas et al., 2018; ICASO, 2007).

Prevalence of HIV among Nigerian Children

In Nigeria, over 220,000 children 0-14 years were living with HIV in 2017 out of which 26% were accessing ART in Nigeria (UNAIDS, 2018). Following poor access to ART, rising mortality among children 10-14 years is the highest compared to other countries in the world (Slogrove et al., 2018).

A major challenge of the HIV epidemic in Nigeria is the number of orphans due to AIDS as 1.8 million children in 2017 were orphaned by AIDS (Robertson & Toole, 2019). These orphans, especially girls, are often faced with a horrifying burden of poor health, irregular school attendance, become caregivers of their HIV positive parents, and are sexually abused (NACA, 2014; Robertson & Toole, 2019).

Prevalence of Perinatal Transmission of HIV among adolescents in Nigeria

According to UNAIDS estimate in 2017, Sub-Saharan Africa accounted for 159,000 out of 180,000 global new HIV infection among children while Nigeria accounted for 23% (36,570) of the regions new HIV infection among children (Olakunde et al., 2019). Thus, indicating a poor implementation of Prevention of Mother-to-Child Transmission of HIV/AIDS intervention in the country. Nigeria does not have estimates specifically for perinatal infection for the age bracket 10-19 years for the period (NACA, 2016). However, Mgbachi (2019) reports that the second most common mode of HIV transmission in Nigeria is through perinatal transmission. In 2014, Nigeria accounted for 33% (58,000) of all new HIV infection among 80% of women living with HIV globally (Pharr et al., 2016). While in 2016, the country accounted for 37,000 out of the global 160,000 newly HIV infected children indicating high rate of mother-to-child transmission and earning a reputation of being the country with the highest number of new HIV infection among children in the world (Cohen, 2018; NACA, 2019; UNICEF, 2017).

Prevalence of Behavioral Transmission of HIV among adolescents

At the global level, 50% of the 35.3 million persons living with HIV less than 25 years of age were infected through sexual transmission (Mgbachi, 2019). In 2017, one million adolescent girls were living with HIV globally and among girls 10-19 years, HIV was among the top five causes of death (UNAIDS, 2018). About 7000 adolescent girls and young women age 15-24 years were infected with HIV virus weekly (UNAIDS, 2018). In Sub-Sahara Africa, one in five new HIV infection were among adolescents and young women age 15-24 years (UNAIDS, 2018).

Following the NAIIS report, females make up the majority of persons living with HIV with a prevalence of 1.9% against their male counterpart with 0.9% across all the geopolitical zones of Nigeria except the North-West zone where the reverse is the case

(NACA, 2019). For HIV burden distribution across the different age groups, 12% of PLHIV are 0-14 years, 75% are 15-49 years, and 13% are 50 years or over; adolescents 10-19 years account for 8% of the HIV prevalence of the country (NACA, 2019). Between the age group 15-44 years, there are more females living with HIV than males (NACA, 2019).

HIV incidence is significantly higher among female adolescents and young adults 15-29 years of age and in adults 30 years and above (NACA, 2019). UNICEF (2019) indicated that adolescent girls between the age of 15- and 19-years test for HIV regularly than adolescent boys of the same age group.

Challenges Associated With Adolescents Living With PHIV and BHIV

Irrespective of the medium of HIV transmission, adolescent girls living with PHIV and BHIV are known to experience daily challenges with the management of their health and treatment of HIV disease, and the psychosocial impact of living with HIV. Understanding these challenges is therefore a pre-requisite for developing appropriate interventions and strengthening of the capacity of service providers to provide context specific quality service delivery to these unique populations. These challenges will be viewed through the SEM lens of personal, family and healthcare constructs.

Personal-Level Challenges

Adherence to ART by Adolescents

The ultimate aim of adhering to ART is to achieve viral suppression, which invariably means reduction in the destruction of CD4 cells, reduced immune suppression and a slowed down rate of progression of the HIV disease (Ugwu & Eneh, 2013). None or suboptimal adherence to medication could lead to the reduction of the survival rate of PLHIV (Anyaike et al., 2019). Although 95% viral suppression rate is considered optimal for treatment success, 80% has been recorded for viral suppression, reduced risk of opportunistic infection and prevention of ART resistance (Adejumo et al., 2015b). Adherence to ARV medication has been a major challenge among ALHIV due to multiple factors such as the fear of unwanted disclosure, inadequate information or misconceptions about the need for good adherence, lack of privacy for those in boarding schools, negative experience with the medication, stigma, delay at health facilities, negative emotional state and limited choices with treatment regimens (Adejumo et al., 2015; Folayan et al., 2015; Galea et al., 2018).

A report by UNAIDS indicates that initiation or adherence to antiretroviral therapy for women or adolescent girls living with HIV may be negatively impacted by intimate partner violence; a higher prevalence of intimate partner violence among adolescent girls age 15-19 years was reported in 16 of 36 countries (UNAIDS, 2018). However, associations between age and adherence were reported in an Ethiopian tertiary health facility where poor adherence level was noted among older children and adolescents as compared with younger children while lower rates of adherence were reported in South Africa among adolescents when compared to adults among 8000 patients receiving ART (Adejumo et al., 2015).

Tshuma (2016); Adejumo et al., (2015), described adherence to medication by adolescents with PHIV as being a very difficult task because health is not a priority for adolescents but the need to have outstandingly organized lives, thus, because of the side effects or many quantities of the drugs they take, burden or pills fatigue set in. This is also complicated by the drugs prescribed to address coexisting conditions experienced by adolescents with PHIV. When comparing ART adherence among adolescents with PHIV and BHIV in Sub-Sahara Africa, research indicates that more studies are focused on HIV perinatally infected adolescents than those behaviorally infected, however, studies in some developed settings show that ART adherence is poorer among adolescents with BHIV than those with PHIV (Chandwani et al., 2012; Dachew et al., 2014).

Health Problems of Adolescents

With long term management of their chronic condition, adolescents with PHIV are likely to have long-term health challenges such as acquired cardiovascular diseases (pulmonary arterial hypertension, heart failure, symptomatic heart failure and atherosclerosis) than adolescents with BHIV which may get more complicated if the HIV stays long without treatment (Lipshultz et al., 2013; Vreeman, Scanlon, McHenry, & Nyandiko, 2015). Also, the different treatment regimens used to improve the lives of HIV patients may also increase the risk of cardiovascular diseases (Lipshultz et al., 2013; Vreeman, Scanlon, McHenry, & Nyandiko, 2015). Tshuma, (2016) identified long term exposure to ART by adolescents living with perinatal HIV as the following, physical complications; skin blemishes, stunted growth, pubertal delay, wasting, and scarring. Vreeman et al. (2015) reports psychological challenges, behavioral disorders and well as mental health issues associated with children perinatally infected with HIV. Treatment-related factors that affects adherence include anticipated or real side effects, taking many quantities of the ART medications (known as Pills burden) have been identified in the

United States and South Africa as the main reasons for adolescents and youths missing their ART medication; drugs prescribed to address coexisting conditions for adolescents living with HIV are said to increase medication burden thereby contributing to poor adherence of the ART medication (Adejumo et al., 2015b).

HIV Status Disclosure by Adolescents

Being initiated on ART does not necessarily mean the adolescent knows his or her HIV status or the reason for daily taking the medicine (Kim et al., 2014; Okawa et al., 2017). This is a major knowledge gap which impacts negatively on ART adherence which when addressed, improves adherence to ART (Kim et al., 2014; Okawa et al., 2017). Since adolescence is a transitioning period requiring social and sexual identity, the need to have friends or intimate relationships is integral to their development process (Nöstlinger et al., 2015). Therefore, HIV self-disclosure of an ALHIV becomes very challenging because of the reaction this may elicit such as HIV related stigma, as indicated in many studies (Evangel & Foster, 2014; Nöstlinger et al., 2015). Self-disclosure of HIV status by ALHIV has been identified as being able to boost self-esteem, improve immunological recovery and psychological well-being (Nöstlinger et al., 2015; Odiachi, 2017).

HIV status disclosure by PLHIV is fundamental to having increased care and support including emotional and financial supports (Folayan et al., 2015), however, there are some identified challenges and risks to HIV disclosure among adults and adolescents living with HIV in Nigeria (Ogoina et al., 2015). The fear of being stigmatized or discriminated against, fear of rejection, and loss of respect among peers are known to be the reasons for non-disclosure and poor uptake of sexual and reproductive health services among ALHIV (Folayan et al., 2015). WHO (2013) reported major barriers to disclosure among ALHIV as fear of unintended or unwanted disclosure by friends, teachers or parents, and lack of privacy in health facilities or pharmacies where they access services and discriminatory behaviors from peers, family, and community where they reside. Fear of disclosure especially in boarding houses and foster homes impact negatively on adolescents taking their drugs (Adejumo et al., 2015b).

To some perinatally infected adolescents, the issue of self-disclosure must be kept secret as this confers some level of control on them, and therefore decides on who should or should not know about their status; this is perceived as a protective mechanism (Madiba & Mokgatle, 2016). This mechanism may be supported by their caregivers, who may have advised the adolescent living with PHIV to maintain secrecy for fear of indirectly exposing the HIV status of the mother which could lead to the household being stigmatized.

Poor Knowledge of HIV/AIDS among Adolescents

Having the correct knowledge about HIV infection and how to prevent it among adolescents empowers them to make informed decisions about their health and sexuality as well as build confidence in relationships (Avert, 2020). Ignorance of HIV/AIDS and some myths and misconceptions at the wake of the HIV/AIDS epidemic were identified as factors that contributed to increase of the disease as some local and national leaders felt the disease was a ploy by Western nations to stop the demographic increase of Africans (Amuche et al., 2017). Hence, some AIDS-related deaths especially in South

Africa, were because of the refusal of antiretroviral drugs for the treatment of HIV (Amuche et al., 2017). Avert (2020), attributed the high HIV infection rate among adolescents excluding those who were perinatally infected as being due to incorrect knowledge about the disease and how to prevent it, thus encouraging them to engage in unprotected sex.

In Nigeria, Mgbachi (2019) reported low knowledge of HIV status among adolescents as a contributory factor which increases HIV vulnerability in adolescents and young persons. This varies across the geopolitical zones with the North-Central having the highest and the Southeast having the lowest. The 2017 State of the World's Children report indicates that only 36% of male adolescents and 30% of female adolescents and young persons (aged 15-24 years) have the accurate information about HIV, hence inferring that comprehensive and correct knowledge of HIV globally among adolescents is low (UNICEF, 2017). In Nigeria, a UNICEF 2015 report indicated that about 34% of male adolescents and 24% of female adolescents have comprehensive knowledge about HIV (Mgbachi, 2019). Thus, there is low level of comprehensive knowledge of HIV among adolescents and young persons as compared to the awareness of HIV/AIDS (Mgbachi, 2019).

Sexual and Reproductive Needs of Adolescents

The desire to be parents increases by the day and is often driven by the desire to have children by older adolescents with PHIV following successful adherence to ART (Fair et al., 2013; Mokgatle et al., 2017). Consequently, adolescents with BHIV have similar desire to have children and be parents, however, both subgroups have similar concerns of infecting their partners and children or fear of dying and living their children as orphans (Badell et al., 2013; Fair et al., 2013). In some studies, the desire to have children coupled with the knowledge of prevention of mother to child transmission override the fear of PHIV transmission (Mokgatle et al., 2017).

In a study by Kaushik et al. (2016) to determine sexual knowledge and high risk behavior of PHIV adolescents compared to HIV-uninfected adolescents at a tertiary-care institution, findings indicates PHIV adolescents engaged more in high risky sexual behaviors, lacked sexual knowledge irrespective of their HIV status, fewer of them were more open to disclosing their serostatus to their first sexual partners and were more likely to obtain information about sex education from healthcare workers and school. Similarly, some studies indicated that adolescents with PHIV when compared with adolescents who are HIV negative, engage in risky sexual behaviors such as early sexual debut, unprotected sexual intercourse, have multiple sexual partners and are not likely to disclosure their HIV status (Toska et al., 2015; Mokgatle et al., 2017). However, some other studies indicated that adolescents with PHIV who know their HIV status will likely use condom at their first sexual experience as compared with those who do not know their status (Carter et al., 2013; Toska et al., 2015). Fair et al. , (2016) indicated that adolescents with BHIV are more likely to engage in high-risk sexual behaviors and more comfortable discussing sex-related issues compared with adolescents with PHIV who are said to be more careful. Irrespective of the differences identified between the sexual and reproductive health (SRH) needs of adolescents with BHIV and adolescents with PHIV, some research participants do not see any difference between the two subgroups indicating that the similarities of living with a common chronic disease as adolescents supersedes the mode of transmission of the disease (Fair et al., 2016).

Family-Level Challenges

The family is an integral part of the lives of adolescents living with PHIV and BHIV as they provide the necessary support system considering the different long term challenges this subpopulation experience especially when managing their health.

Characteristics of Families of Adolescents Living With Perinatal HIV/AIDS

There are structural as well as functional effects of HIV in families living with adolescents with PHIV infection. With the death of a caregiver or a caregiver who is living with HIV, a child may have to move to another family thereby rearranging the family structure as well as its functioning;its ability to cope with chronic health conditions (Louthrenoo, Aurpibul, Oberdorfer, & Sirisanthana, 2018). Some of these adolescents depend on the family members for access to treatment, cost of transportation to access treatment especially in far-to-reach health facilities (National Agency for the Control of AIDS, 2016). In determining the factors influencing adherence to pediatric ART in Port Harcourt, South-South Nigeria, Ugwu and Eneh (2013) identified caregivers' factors as being responsible for non-adherence to ART such as drugs finishing, forgetfulness and traveling. Others include the refusal of drugs by children, vomiting and child sleeping (Ugwu & Eneh, 2013).

Risk factors associated with low-income families functioning in chronic health conditions such as those described in this study include fewer children in the home, lower household income and older child age (Louthrenoo et al., 2018). There are reports indicating families most hit by HIV globally are from minority groups, vulnerable population and disempowered families, thus emphasizing poverty as one of the characteristics of families of adolescents living with PHIV infection (Tshuma, 2015).

Low psychosocial support is associated with such families defined as “fractured households” with single parents who may be HIV positive (Galea et al., 2018) or absent parents, thus adversely worsening the ability of such families to cope with their chronic health conditions (Tshuma, 2015) of both adolescents with PHIV and BHIV. Louthrenoo et al. (2018) reported an association between parent-adolescent family functioning discrepancies with an increased risk of HIV risk behaviors in adolescents.

Despite the potential benefits of the importance of HIV status disclosure by caregivers of children and adolescents who are living with HIV, which includes improvement of treatment adherence and psychosocial development, caregivers and health care workers who provide services still find it difficult to disclose the HIV status of these children and adolescents to them (Ubesie et al., 2016). Galea et al. (2018) identified sub-optimal relationship between caregivers and their PHIV adolescents, and fear of stigma as the major challenges expressed by caregivers in relation to HIV status disclosure. Interventions to address the challenges peculiar to ALHIV should incorporate strategies to elicit sufficient information on caregivers’ challenges in managing the crisis their children face and provide support to helps cushion such challenges.

Some challenges expressed by caregivers especially by those who are HIV positive single parents which affects the support they provide to their HIV positive adolescents is insufficient or lack of economic resources (Galea et al., 2018). Toth et al.

(2016) discussed the positive contribution of social protection intervention to ART adherence and general wellbeing of ALHIV such as food security, availability of school fees and school feeding programs and cash transfer. Ubesie et al. (2016) indicated reasons for low disclosure rate at the University of Nigeria Teaching Hospital, Enugu as caregivers or parents not being provided with sufficient information on the disclosure process, inability for the country to streamline disclosure counseling into its comprehensive management of pediatric HIV/AIDS guidelines, and caregivers or parents fear of health and emotional consequences, as well as stigma and discrimination.

Difficulty with disclosure of HIV status to children was identified to be a major challenge with caregivers who have adolescents living with perinatal HIV; some thought their children were too small to understand the concept of HIV/AIDS, some feared their children may disclose their status to neighbors or persons in the community or school and then get stigmatized or be discriminated against (Kidia et al., 2014), while some felt a sense of guilt for infecting their children while some felt they may not be able to provide answers to some questions that may arise from the disclosure (Folayan et al., 2015; Galea et al., 2018). No matter the challenges expressed or experienced by caregivers and parents, Gyamfi et al. (2017) asserted that as a fundamental human right as indicated in article 24 of the United Nations Convention on the Rights of the Child, caregivers and parents are to provide accurate information to children living with HIV.

Community-Level Challenges

Access to HIV/AIDS Treatment

Surveys conducted among adolescent girls and young women and other persons living with HIV indicated that stigma and discrimination at the hands of health care providers prevent them from accessing HIV care services or stay engaged in such services (UNAIDS, 2018). Some adolescents living with HIV expressed their concerns on the availability of HIV services at health facilities in Lesotho during school hours that made it difficult for them to access treatment (Adejumo et al., 2015a; Anyaike et al., 2019; Davey, 2007; Galea et al., 2018; MacCarthy et al., 2018; Ugwu & Eneh, 2013). Health system delays which have resulted in missed work, wages and schooling, have also been expressed by some caregivers and adolescents in Peru (Galea et al., 2018).

For HIV positive adolescents who are not aware of their HIV status, high age of consent is a barrier to HIV counseling and testing and subsequent access to HIV/SRH services in Sub-Sahara Africa (Mugo et al., 2016; National Agency for the Control of AIDS, 2016). The Nigeria National HIV strategy for adolescents and young people 2016-2020 indicated that treatment services designed for adolescents are not youth-friendly due to limited capacity and negative attitude of service providers (National Agency for the Control of AIDS, 2016). Other challenges with access to treatment includes drug stock-outs, insufficient health care workers with specialty in providing HIV treatment, care and support services, loss to follow up (LFTU) among adolescents experienced during transition from pediatric to adult clinical services, and hospital or clinical, administrative cost mostly charged for opening hospital or clinic file, consultation, and drugs including ARV (National Agency for the Control of AIDS, 2016).

Gender Issues and Gender-Based Violence

Specific to adolescent girls and young women are gender discrimination and gender-based violence known to fuel the HIV epidemic; these have impacted negatively on the ability of these population to protect their health, prevent HIV, make informed decision as it pertains to their sexual and reproductive health and lives as well as seeking other health services (UNAIDS, 2019). There are studies indicating differences in the manner male adolescents communicate their health needs and manage their care and treatment; many reports indicating ART non-adherence among female adolescents living with HIV when sick can be attributed to the challenges they experience managing their care which also includes communicating their medical concerns with health care workers who attend to them (Toth et al., 2018). This brings to the fore, the need to be gender sensitive in planning and implementing interventions for ALHIV, build the necessary communication skills and ensure a cordial patient-healthcare workers relationship in healthcare settings.

Violence or the fear of violence experienced by girls and women also impede disclosure of HIV status to family members, health care workers, and partners (UNAIDS, 2018). Studies show that girls and women who have experienced intimate partner violence are more likely to acquire HIV compared with women who have not experienced such violence (UNAIDS, 2018). Gender inequality as it pertains to sexual issues is a problem that increases HIV infection as women are in weak position to negotiate safer sex due to male dominance (Amuche et al., 2017).

Cultural Beliefs and Discrimination

HIV related stigma because of some cultural and religious beliefs such as the believe that HIV is a divine punishment, witchcraft or the outcome of a life of sexual promiscuity has contributed to the widespread of the disease (Adejumo et al. 2015). There is widespread difficulty in discussing sexual reproductive health issues among children in Nigeria due to unfriendly cultural norms as adolescents with PHIV infection who may be on ART may have been ill-informed of their health status by their parents or guardians (Folayan et al., 2015). These parents or caregivers may not have the required skills to disclose their HIV status to them or may be afraid of how they may react, or may feel some guilt for infecting the child with the virus (Folayan et al., 2015). Discriminatory practices against persons living with HIV prevents them from accessing prevention and treatment services (Amuche et al., 2017: Kharsany & Karim, 2016). Stigma and discrimination have prevented HIV patients from accessing healthcare, and some families, churches and marriage institutions have discriminated against these persons in the region (Amuche et al., 2017).

Healthcare-Level Challenges

Health care workers are vital to the achievement of epidemic control among children and adolescents living with BHIV and PHIV, especially towards assisting these groups of individuals in navigating their care and treatment to transition to adult care and live healthy lives successfully with their viral load suppressed. However, the National

HIV Strategy for adolescents and young people (2016-2020) identified drivers of the epidemic among adolescents and young people as sexual coercion, concurrent sexual partners, low-risk perception, transactional sex, intergenerational sex, and concurrent sexual partnerships (National Agency for the Control of AIDS, 2016).

Poor Health Care Management Systems

Some healthcare workers (HCWs) in Nigeria have reported inadequate training on pediatric HIV services, lack of formal operational guidelines on the provision of appropriate child-focused HIV services to children and caregivers, lack of child-friendly environment and lack of child-friendly job aids for effectively communicating age-appropriate messages to adolescents as major barriers to providing quality services to adolescents living with HIV (Mutambo & Hlongwana, 2019). Mutambo & Hlongwana (2019) also reported the fear of litigation and the unpleasant nature of the medication available to children and adolescents as concerns expressed by healthcare workers which hamper their role as care and service providers.

The consequences of not establishing and maintaining an efficient intra-facility relationship among the multidisciplinary team of HCWs in health facilities that attends to ALHIV can be seen in the quality of care and treatment provided by such facilities; notable among them is lack of trust, unprofessional method in disclosing HIV status to adolescents, increase in lost to follow up and increase in the psychosocial burden of the adolescents living with HIV (Koerichet al., 2015).

Treatment Peculiarities With Adolescents Living With Perinatal HIV

Folayan et al. (2018) asserted that adolescents living with PHIV are exposed to 'high risk of treatment failure and multiclass antiretroviral (ARV) drug resistance' (p. 5) because of socioeconomic challenges associated with orphanhood which could pose a major challenge of adherence to medication. Peculiar to adolescents with perinatal HIV infection are the experience of changing HIV treatment regimen many times before transitioning to adulthood, difficulty in changing from a clinic where they have received comprehensive HIV treatment services and built trust over the years with the clinic staff to start a new relationship in adult clinic (Cruz, 2015; Folayan et al., 2015; Tepper, Zaner, & Ryscavage, 2017). Thus, the need to address the challenges experienced by adolescents living with HIV in transitioning 'from a more forgiving and accommodating pediatric clinic to an anxiety-and fear-producing adult clinic' (p.5) cannot be overemphasized (Folayan et al., 2015).

Poor Access to Sexual Health Services and Adolescent-Friendly Services

The discriminatory environment created by the negative attitudes of care providers coupled with limited access to adolescent-friendly services, and low HIV awareness, were identified as challenges inhibiting adolescents and young persons from accessing sexual health services (NACA, 2015). The adolescent-friendly centers provides avenue where adolescents can have better information about their sex and sexuality, especially as they go through puberty (Folayan et al., 2015). However, family and friends of ALHIV, when viewed from an ecological framework where the adolescent is circled with friends, family, community and the social environment, remains critical in providing learning about sexual and reproductive health (Folayan et al., 2015).

Support groups for ALHIV which are known to provide social cohesion, psychosocial support, and promote adherence to medication have been insufficient in Nigeria and mostly exist in secondary or tertiary health facilities (National Agency for the Control of AIDS, 2016). ALHIV in South Africa with supportive networks such as relatives and peers contribute to good ART adherence while the decline in caregiver involvement in encouraging ALHIV to adhere to their medication especially for perinatally infected ALHIV are threatened by social, developmental and psychological factors (Adejumo et al., 2015b). Psychosocial challenges for horizontally HIV infected adolescents that could impede ART adherence include poor social support, not recognizing the need for medications, substance abuse and fear of disclosure (Adejumo et al., 2015b).

Disclosure of HIV Status by Health Care Workers

Because of the accuracy of the information, they will receive which reinforces the severity of the illness, Kidia et al. (2014) reported that some adolescents with PHIV prefer HCWs to disclose HIV status at the clinics to them as compared to disclosure by their caregivers. This establishes a strong and longtime relationship between the adolescent with PHIV and the pediatric team in health facilities especially in situations where caregivers or family members of these adolescents may have died (Tepper et al., 2017). However, following guidelines for disclosure, the HCWs encourage caregivers/parents to provide disclosure to their children. This notwithstanding, there are still challenges with disclosure of HIV status to ALHIV by caregivers and healthcare workers.

Provision of Differential Treatment and Care

In providing psychosocial support as well as medical services to adolescents living with HIV, (Dowshen & D’Angelo, 2011) expressed the need for HCWss to identify and understand the two distinct populations of ALHIV and to tailor services based on their peculiarities; those perinatally infected and those behaviorally infected with HIV. These sub-populations of PLHIV may face similar challenges but there is the need to provide for their clinical and psychosocial needs differently (Dowshen & D’Angel, 2011). Adejumo et al. (2015) indicated that some studies show that adolescents living with PHIV infection have better ART adherence compared with adolescents living with BHIV infection in developed settings.

For optimal outcomes when addressing the need of adolescents living with PHIV and BHIV, emphases should be placed on multidisciplinary on-site care with a focus to providing for the developmental (psychosocial) need of ALHIV, build adolescent-friendly environment, and apply a family-centered approach.

Summary

With the growing population of adolescents living with PHIV and BHIV in Nigeria, little is known about the lived experiences of this sub-population as they transition into adulthood. Although extensive research on the interplay between adolescents and HIV has been recorded globally, and despite the contribution of PHIV to the incidence of HIV in Nigeria, there is paucity of research on the effect of long-term exposure to perinatal transmission of HIV (Mbachi, 2018) and ART, and lived experiences of adolescent girls living with PHIV and BHIV as it relates to access to HIV services. The literature researched in this chapter outlined the experience of this sub-population in other countries which indicates the dearth of literature on the subject matter in Nigeria. The literature also indicated the prevalence of HIV in Sub-Saharan Africa and Nigeria, and among adolescents living with PHIV and BHIV. This chapter explored literature written about the challenges experienced by adolescents living with perinatal PHIV and BHIV using the SEM across personal, family and health facilities constructs. Chapter three will describe the research methodology and research protocols.

Chapter 3: Research Method

Introduction

There are many studies describing HIV intervention among adults living with HIV in the United States and Sub-Saharan Africa, however, there are not enough studies describing the lived experiences of adolescent girls living with PHIV. It is imperative to understand the personal challenges adolescent girls, aged 15-19 years and living with PHIV, face accessing HIV services and adhering to ART including the influence of their families and the health facility where they receive services. The study also sought to understand the impact of long-term exposure to HIV and ART by adolescents with PHIV (see Comley-White et al., 2019). This chapter describes research methodology used in the study with focus on the research approach, participant selection criteria, data description and collection, data analysis as well as the role of the researcher in all the listed activities. This research was carried after Walden University IRB approval was received.

Research Questions

RQ1: What is the lived experience of Nigerian girls living with PHIV regarding personal, family, and social challenges in access to health services and adherence to ART?

RQ2: What is the lived experience of family members of Nigerian girls with PHIV regarding access to health services and adherence to ART?

RQ3: What is the lived experience of healthcare workers regarding Nigerian girls' access to health services and adherence to ART?

RQ4: What are the perceptions of Nigerian girls with PHIV, their family members, and healthcare workers regarding how HIV services for adolescent girls could be improved?

Research Design

Rationale for Phenomenology

The purpose of the study was to describe the lived experience of adolescent girls living with PHIV infection, their primary caregivers, and their health care workers. The most suitable method for a study of experience is a qualitative phenomenological approach, which allowed me to create a picture of the experiences and the lives of a population, in this case, adolescent girls living with PHIV. I collected my data through one-on-one interviews, using open-ended questions and responses (Creswell, 2018). From the picture of the experiences described, the perception of adolescent girls living with PHIV was extracted. Data collection using this approach emphasizes the need to delve deeply into the phenomenon being studied to gain depth through personal reflection of the participants (Creswell, 2018).

As a philosophical movement inspired by Edmund Husserl (1970), phenomenology is centered on the concept of *epoche,* meaning *freedom from suppositions.* It is based on an understanding that people's knowledge of things is based on their past experiences and reflections (Welton, 1999). Husserl (1970) believed that the lived experiences of human beings can also be derived through observations while remaining neutral in the process. Husserl opined that the perception of one's experience provides knowledge on that experience, and that knowledge of any phenomenon is best based on input from people who have directly experienced the phenomenon themselves (Burkholder et al., 2016). Hence, researchers must identify their own biases and the impact of such biases on the data to be analyzed, and then purposely separate those biases (Burkholder et al., 2016).

While other forms of qualitative research may provide a partial view of human experience of a phenomenon, phenomenology provides direct understanding of people's experiences of a phenomenon through their perception of the phenomenon to place it within a context (Burkholder et al., 2016). It therefore means that phenomenology recognizes the significance of a first-person perception (Creswell, 2003) and determines the transferability of experiences from one person to another within the same circumstances, background, or context (Burkholder et al., 2016).

My aim was to understand the challenges adolescent girls experience as it relates to PHIV as phenomenon of study. Other researchers have also used phenomenology to understand similar phenomena. For example, Appiah et al. (2019) provided an account of the experiences of children and adolescents from Northern Ghana on HIV disclosure using a phenomenological approach. With the aid of phenomenological analysis, Appiah et al. (2019) identified several challenges to HIV disclosure by children and adolescents ranging from preference by caregivers to disclose HIV status to children when they grow older, severity of illness and disease progression that informed the need for disclosure, to caregivers having little or no plans to disclose HIV status to their children (Appiah et al., 2019). Similarly, Otieno and Obuya (2019) used phenomenology to determine the communication experience of adolescents living with HIV/AIDS and how they perceive their experiences. The phenomenological analysis revealed that adults do not provide enough opportunities for adolescents to communicate their feelings and experiences but rather bore them with series of advice, messages, threats, commands, and lectures (Otieno & Obuya, 2019). Otieno and Obuya (2019) concluded by asserting that adults are not conversant with the reality of life of adolescents living with HIV and so these adolescents do not have the platform to express their communication needs.

Role of the Researcher

My first experience in the field of public health was working with the World Health Organization and the Nigeria Program on Immunization in the late 1990s (1999) to facilitate the immunization of children under 5 against poliomyelitis. As a central facilitator (field consultant), I had the privilege of working mostly in the rural areas of the north and middle belt of Nigeria and witnessed firsthand the challenges caused by poliomyelitis in the lives of little children and their caregivers. The pain and stigma of polio experienced by these children was overwhelming, as their caregivers bore the burden at home, the community and possibly schools.

Additionally, in my capacity as a public health professional, I have worked with orphans and vulnerable children (OVC; children and adolescents) from HIV infected and affected households in the different parts of Nigeria for over 13 years where I witnessed the plights of this population especially the effect of HIV on them and their caregivers. Some children fell ill regularly while some died because no one suspected they were infected with the HIV virus or only realized at a very late stage that they had been perinatally infected. Some of the caregivers of these children were either afraid to disclose to their children their own HIV status and instead resorted to visiting traditionalists (local native herbalists) for treatment using local herbs, or the grandparents of these children as caregivers only realized the HIV status after the death of the parent (oftentimes, single parents). Some grandparents only realized their grandchildren were perinatally infected after they may have tried all traditional means to get their grandchildren healed of a "mysterious illness" that refused to go, and only then enrolled the children in an HIV/AIDS program that tested and treated HIV positive children and their caregivers. I often wondered about the experience of these children living with PHIV and BHIV infection, and the effect of the virus on the family structure and wellbeing, especially on the children, their caregivers, the health facility where they were treated, and on the community, where stigma and discrimination are common.

As a Senior Program Manager on an HIV/AIDS project that seeks to improve case-finding and retention in care for children and adolescents in seven states and the Federal Capital Territory, where I currently reside, I have extensive experience working with children and adolescents across different thematic areas in public health. My study will explore the plight of this population, and hopefully contribute to the provision of suitable interventions that can improve the conditions of this population as well as assist them to live healthier lives. I was responsible for recruiting eligible participants with assistance from health facility staff, identification and engagement of research sites, the facilitation of the various interviews in line with the social ecological model described in chapter one, and the analysis of data collected. To manage possible bias, I ensured the participants were randomly selected from a pool of adolescent girls living with PHIV in the identified health facility. This led to the identification and selection of the caregivers of eligible adolescent girls for the study. I anticipated a power imbalance between myself and the participants, since I was viewed as the professional in the field. This was addressed by ensuring the participants were in control of their decision to participate and had the choice to withdraw from the study at any time without reproach (Kay, 2017). Also, I ensured the participants were not coerced to answer questions, avoided facial expressions or gestures that may lead the participants (Burkholder et al., 2016). To ensure all participants expressed their own experience void of any influence by me, the process of bracketing, which involves identifying and separating the ideas or opinions of the researcher to stick closely to the phenomenon as experienced, during data collection and analysis, was employed as recommended by Morrow et al. (2015). In this way, biases, personal experiences and perceptions of the research team were bracketed.

Methodology

Participants Selection

Participants for this investigation were adolescent girls aged 15-19 years living with PHIV and accessing HIV treatment in a Faith-based health facility in the Federal Capital Territory, Nigeria with history of compliance with antiretroviral treatment). Caregivers of eligible adolescent girls living with PHIV and health care workers providing HIV services to these adolescent girls at the health facility were selected using purposive sampling.

The following inclusion criteria was used for the girls: Adolescent Nigerian girls aged 15-19 years; living in the Federal Capital Territory, accessing ART services and participating in a support group at the health facility for not less than 2 years; have a history of compliance with ART (Galano et al., 2016).

Inclusion criteria for caregivers, were as follows: primary caregiver; could be a reactive or non-reactive primary caregiver; biological parent or relative of adolescent girl living with PHIV whose ward or daughter was receiving HIV services at the same health facility for not less than two years.

Inclusion criteria for HCWs were as follows: HCWs at the same health facility, involved in providing direct services to adolescent girls living with PHIV for not less than two years.

Exclusion criteria for the girls were age below 15 or over 19 years of age, and not a brothel and non-brothel based female adolescent sex workers.

Considering the nature of adolescents living with PHIV, the fear of stigma and confidentiality issues that could arise during identification of the research participants, the difficulty of identifying these group of people from the different constructs of the SEM being used for the research, the sample size was determined through theoretical sampling (Baker et al., 2012). Theoretical sampling affords the opportunity of purposely interviewing participants from the adolescent support group at the health facility, their caregivers (parents/guardians), health facility personnel who provide healthcare services at the facility. I ensured that relevant information as they pertain to the phenomenon being studied were gathered (Pratap, 2018). Data saturation was attained when the “depth as well as the breath of information” were achieved (Creswell, 2018; Hennink, Kaiser, & Marconi, 2017; Pratap, 2018); when there was no new information that could contribute to already generated information (Pratap, 2018). Theoretical saturation was attained when no new properties and dimensions emerged from the data and the analysis accounted for much of the variability (Pratap, 2018).

Burkholder et al. (2016) recommended a sample size of 8-12 participants for phenomenological research; larger numbers do not produce more insights into the experience of the participants. However, the final number depends on when the data become saturated. Adolescent girls living with PHIV were selected for the study to respond to research questions 1. In addition, caregivers and healthcare workers at the facility were recruited and interviewed regarding research questions 2 and 3 respectively. Responses to research question 4 were extracted from responses provided by the adolescent girls with PHIV, the caregivers and the healthcare workers. In total, I interviewed 9 participants (Table 1).

Table 1

Number of Participants by Category

Category of Participants	Number of Participants
Adolescent girls living with PHIV	3
Primary caregiver of adolescent girls with PHIV	3
Healthcare workers of girls with PHIV	3
Total	9

Instrumentation

The main data collection instrument for the study was the interview protocol (Appendix F, G, H) which includes the interview questions for adolescent girls with PHIV, primary caregivers of the adolescent girls with PHIV and HCWs providing HIV services to these girls. The interview protocols were designed to align with the nine interviews used to elicit rich information from the different participants following the social ecological systems theory constructs. These includes questions for each category of participants to guide the researcher in the field through semi-structured interviews with open ended questions. This aligns with best practice to ensure the researcher asked questions that aligned with the research questions and probed further to elicit deeper information on the experience of the participants (Burkholder et al., 2016). As appropriate, face-to-face interviews was employed in the study. Because face-to-face in-depth interviews are appropriate for eliciting sensitive information on sensitive topics that would not have been provided if the interview was conducted in a group, this was appropriately employed. In this case, interviewing adolescent girls living with PHIV in Nigeria, provided insights into important personal and social issues by understanding their experiences, those of their family, and the healthcare providers who relate with them.

I ensured the participants were screened to identify those who could speak English. All participants who met the selection criteria were recruited into the study.

Procedures for Recruitment, Participation, and Data Collection

The recruitment process commenced after the receipt of approval from Walden University's IRB. The Health Coordinator of the health facility in the Federal Capital Territory of Nigeria was contacted and provided with detailed information of the study with a view to obtaining approval as the gatekeeper of the facility, and request for the release of relevant HCWs from the unit providing HIV/AIDS services to HIV positive adolescents, to participate in the research. This provided the opportunity to seek the assistance of the relevant HCWs to recruit adolescent girls living with PHIV as well as their biological parents or guardians who serve as caregivers. Following a written approval from the Health Coordinator, the recruitment process commenced which was guided by the inclusion and exclusion criteria already developed. Potential participants were contacted from a pool of participants selected by the database officer at health facility using the inclusion and exclusion criteria and shared with the me. I then contacted all potential participants and selected those eligible to be interviewed. Informed consent forms were sent to all participants shortlisted to be interviewed.

Considering the sensitivity of the questions developed, the invitation sent to the participants included information stating the purpose of the study and its intended benefits and possible risk (Galano et al., 2016) to the participants which could be psychological or emotional stress, and assurance of confidentiality; that the identity of the participants will not be made known to persons outside the study. Opportunity to ask questions with phone numbers and person to contact in this regard, was provided in the invitation sent to the participants. A professional counselor was engaged to provide counseling (psychosocial support) to adolescent girls and their caregivers who may need such support due to the sensitivity of the questions developed. Prior to the administration of the interview questions, all questions were reviewed and approved by the Chair of the dissertation committee at Walden University.

The plan to collect data was along the different constructs of the social ecological systems theory; from adolescent girls living with PHIV, the family of the adolescent girls living with PHIV, and the HCWs providing treatment to these group of persons. Data was collected via face-to-face interview that lasted over 1hour for most of the participants. All interviewees were informed that they were free to leave at any time without prior notification or explanation, and that their participation was strictly voluntary (Kay, 2017). Since the interview was semi-structured, probing for in-depth information regarding the experiences of the participants was used while bracketing assisted to indicate any information not provided by the participants such as views, observations or experience of the researcher (Burkholder et al., 2016). Each of the interviews were recorded electronically and saved in a recorder for transcription after seeking for and obtaining permission from all the participants. To minimize risk of inappropriate disclosure of personal information, data was de-identified as soon as possible. This involved the removal of all direct identifiers such as names, addresses, telephone numbers from the raw data and database. Necessary precautions were taken not to disclose to anyone else any part of the data that could be linked to a participant's identity. Provision was made to have a telephone interview with any of the participant who may not be disposed to having a face-to-face interview with the researcher.

In the event I did not achieve data saturation, a follow-up plan was put in place for recruitment of more participants (Creswell, 2018; Hennink et al., 2017). During the debrief section of the interview, all participants were informed that all research materials such as audiotapes, transcripts, and any other confidential information used during the investigation was be stored by me. However, information was provided to all participants and the health facility personnel that Walden's IRB or the dissertation committee may at any time request for access to the raw data; transcripts, audio recordings (Kay, 2017).

Procedures for Data Analysis

As data collection commenced, so was the analysis which enabled me to produce better and more detailed follow up probes to generate very rich information from all participants, as recommended by Burkholder et al. (2016). All responses from the research participants which were audio-recorded, and field notes were reviewed and transcribed verbatim in line with the research questions in preparation for analysis using manual coding. Themes were generated using Colaizzi's method, which describes a seven-step process of rigorously analyzing qualitative data to achieve a concise but very rich description of the phenomenon being studied and validated by the participants that generated the data in the first place (Morrow et al., 2015).

Issues of Trustworthiness

Trustworthiness, also referred to as validity emphasizes on the need for rigor as a key component of qualitative research; the more rigorous the research process, the more trustworthy the results of the findings (Ravitch & Carl, 2015). Rigor defines quality in the research process and is necessary in the study of individual lived experiences which must be structured and within context and must follow a methodological rigor (Ravitch & Carl, 2015). Credibility, transferability, dependability, and confirmability are the four primary dimensions of trustworthiness as they assist the researcher to have an understanding, engage and plan for the various trustworthiness (Shenton, 2004; Ravitch & Carl, 2015)

Credibility

Credibility is a fundamental part of trustworthiness which tends to know if findings are consistent with reality (Shenton, 2004). I achieved this by designing the interview guide to include iterative questions that were open ended, employ a recruitment and data analysis methods derived from similar studies (Shenton, 2004). The use of Purposeful sampling for the selection of participants also ensured credibility as a good representation of the target participants. Data triangulation through comparison of primary data from the research participants with other data sources such as from similar research work allows for the verification of information provided by individual participants with others (Shenton, 2004). Credibility was further enhanced by employing member checking technique; sharing the findings of the study with the research participants to ensure they are accurate and aligns with their experience (Birt et al., 2016).

Transferability

Comparing the findings of the study with those of similar research infers that such findings can be applied to similar populations, situations or phenomenon while still retaining the richness of the context (Statistic Solutions, 2017; Ravitch & Carl, 2015). To achieve transferability, there was the need to provide detailed description of the data and context to allow for comparisons with other context based on the rich information provided (Ravitch & Carl, 2015). Transferability in this study was achieved by providing rich information about the context of the study as they relate to the situation especially the fact that stigma and discrimination are major hinderances preventing the update of HIV services by adolescent girls living with PHIV at the different levels of the social ecological systems theory, in the Federal Capital territory of Nigeria (Ravitch & Carl, 2015).

Dependability

Dependability is similar to reliability in quantitative research and refers to the stability of data generated in a qualitative analysis; the application of reasoned argument in the collection of data and ensuring data aligns with the argument (Ravitch & Carl, 2015). The stability of data here, refers to its ability to answer the research questions in the study (Ravitch & Carl, 2015). The attainment of dependability in qualitative research is dependent on the fact that the study can be repeated by another researcher and the similar findings achieved (Shenton, 2004). The research provided a full account of the processes followed especially in line with similar studies using the same qualitative approach, to ensure dependability. For the dissertation, I ensured proper documentation of the processes from the research design to its implementation; details on how data was collected and information about the field work especially from memos and journals, and the reflective appraisal of the study which was fundamental to determining the effectiveness of the phenomenon being studied (Shenton, 2004).

Confirmability

Confirmability is like objectivity in quantitative research (Ravitch & Carl, 2015). The degree of neutrality in the study depicts what is defined as confirmability (Statistics Solution, 2017); the need for the researcher to seek to have confirmable data free from all forms of researcher's biases (Ravitch & Carl, 2015). The neutrality of the researcher defines the objectivity of the research; the fact that the findings are not based on any personal motivation or potential bias (Shenton, 2004). To ensure confirmability, I showed that findings from the research were based on the responses of the participants; this was evident from the data collection process to the analysis showing the identification of themes and meta-themes which clearly shows the sequence of the findings from the participants responses. For the dissertation, confirmability was ensured through the documentation of all daily processes using journals.

Ethical Procedures

To ensure compliance with ethical procedures, approval from the Institutional Review Board at Walden University was sought and obtained prior to the commencement of participants recruitment. Basic ethical principles of respect of persons, beneficence and justices as enshrined in Belmont Report as it pertained to research involving human subjects (Office of Human Research Protections, 2018) were followed when conducting the study. To adhere to the principle of respect of persons, the research participants were provided with enough information to make informed decision to participate voluntarily in the study without any coercion (Office for Human Research Protection, 2018). Participants were given the option of ending the interview if they feel any form of discomfort, harm, or risk. Hence, the benefit of the research to the participants which includes creating awareness on the plight of adolescents living with PHIV and providing the pathway for developing appropriate interventions to address the socio-developmental needs of this sub-population, was read to all participants. A female professional counselor from the health facility was engaged to provide some form of psychosocial support when needed. To ensure justice, all participants were treated equally, and any identified needs addressed within the health facility to ensure confidentiality.

Informed consent was obtained from all parents or guardians of the adolescent girls who participated in the study, which contains the purpose of the study along with assurance of confidentiality and how this was maintained, and how the interview transcripts was protected. Adolescent girls living with PHIV aged 15-17 years participating in the study were asked to complete an assent form before the commencement of the interviews. All transcribed interviews were secured in an electronic devise with strong username and password.

Summary

The study was designed to understand the experience of adolescent girls living with PHIV in accessing HIV services and adhering to ART using social ecological systems theory consistent with phenomenological research approach. The participants include adolescent girls aged 15-19 years living with PHIV, their mothers (as caregivers) and HCWs from a faith-based health facility in the Federal Capital Territory, Nigeria. Data was collected using semi-structured interviews (In-depth interviews), transcribed using electronic audio system, and analyzed using Colaizzi's method for identification of codes, categories, theme and meta-theme analysis. The results of the study, including themes and meta-themes, are presented in Chapter 4 and discussed in Chapter 5.

Chapter 4: Results

The purpose of the study was to explore the lived experience of adolescent girls living with PHIV in Nigeria in accessing services and adhering to medication. The study also sought to understand the impact of long-term exposure to HIV and ART by adolescents with PHIV (see Comley-White et al., 2019) and how the barriers and facilitators of access to care affected adherence and access to ART (Galea et al., 2018). This was a phenomenological study using Colaizzi’s (1979) seven points guidelines for the phenomenological analysis of interview data.

Below are the four research questions that guided the study.

RQ1: What is the lived experience of Nigerian girls living with *P*HIV regarding personal, family, and social challenges in access of health services and adherence to ART?

RQ2 What is the lived experience of family members of Nigerian girls living with PHIV regarding access to health services and adherence to ART?

RQ3. What is the lived experience of healthcare workers regarding Nigerian girls’ access to health services and adherence to ART?

RQ4. What are the perceptions of Nigerian girls with PHIV, their family members, and healthcare workers regarding how HIV services for adolescent girls could be improved?

This chapter has six sections: the setting, demographics, data collection procedure, data analysis, evidence of trustworthiness, and results.

Setting

Recruitment of participants for this study took place between February and March 2021 from the same health facility. I contacted the health facility in July 2020 with a letter introducing the study and asking for permission to conduct the study at the facility including the recruitment of participants. Following the approval and the issuance of a letter of cooperation by the health facility, I commenced discussions with the ART Coordinator and the Monitoring and Evaluation Officer (M&E)/database officer to have access to data of possible participants. This included adolescent girls with PHIV, their caregivers, and the healthcare workers who provide services to them at the health facility.

Following the recruitment criteria, a pool of eligible caregivers of adolescent girls with PHIV were selected by the M&E Officer and shared. Interested caregivers from the pool were provided a phone number with which they could express interest in participation. Final eligible adolescent girls with PHIV and their caregivers were recruited as research participants followed by the recruitment of healthcare workers who may have provided services to them, in a triad. Face to face interviews were conducted at the facility in a private room for all categories of participants as their choice with strict adherence to the COVID-19 prevention protocol. Audio recording for the interviews were conducted for all categories of the participants followed by verbatim transcription and member checking.

Demographics

A total of 9 individuals participated in the study across three categories of participants: (a) adolescent Nigerian girls with PHIV age 15-19 years living in the

Federal Capital Territory, accessing ART services and participating in a support group at the health facility for 2 years or more, and with a history of compliance with ART treatment; (b) caregivers, including biological parents or relatives of the girls living with HIV, who had been receiving HIV services at the same health facility for 2 years or more; and (c) healthcare workers at the health facility who had been providing direct services to the girls with HIV for 2 years or more. Tables 2-4 provide the characteristics of the participants.

Table 2

Adolescent Girls With PHIV

S/N	Participant code	Age	Years on Treatment	Level of Education
1	Adolescent girl 01 (AG1)	15	10+	Senior Secondary School 3
2	Adolescent girl 02 (AG2)	17	8+	Senior Secondary School 2
3	Adolescent girl 03 (AG3)	18	10+	Senior Secondary School 3

Table 3

Caregivers of Adolescent Girls With PHIV

S/N	Participant code	Age	Years on Treatment	Employment Status
1	Caregiver 01 (CG1)	35 - 40	13 years	Volunteer at a CBO
2	Caregiver 02 (CG2)	35 - 38	14 years	Domestic worker
3	Caregiver 03 (CG3)	35 - 40	14 years	Housewife

Table 4

Healthcare Workers

S/N	Participant code	Gender	Years of experience as HCW	Designation
1	Healthcare Worker 01 (HCW1)	Female	15 years	Nutrition Counsellor
2	Healthcare Worker 02 (HCW2)	Female	7 years	Home BCare Officer
3	Healthcare Worker (HCW3)	Male	8 years	Clinician

Data Collection

Participants

A total of 24 eligible caregivers whose adolescent daughters 15-19 years with PHIV and BHIV were originally identified by the health facility following the initial inclusion criteria PHIV and BHIV. However, only one caregiver had an adolescent girl with BHIV. Only adolescent girls with PHIV, and their caregivers and health workers were selected and interviewed for the study.

Location, Frequency, and Duration of Data Collection

I completed nine interviews across the three categories of participants for the study namely, the adolescent girls with PHIV, their caregivers, and healthcare workers who provide HIV services to ALHIV. Prior to the commencement of data collection, permission to collect data from human subjects was obtained from Walden University's IRB on the 12th of January 2021 with the approval number 01-11-21-0273718. Following the IRB approval and issuance of letter of cooperation by the health facility, the ART coordinator for the health facility, the adherence counsellor, and the M&E/Database

Officer were contacted. Subsequently, I scheduled an orientation meeting to discuss the study and research protocol and then provided the confidentiality agreement form for signing. This enabled these staff to commence the identification of potential research participants from the facility’s database using the inclusion criteria to generate a pool of 24 caregivers of adolescent girls with PHIV as potential research participants. The database officer reached out to these caregivers to inform them of the study and that I would later call them on phone to provide the full details of the study. A list of interested caregivers was then prepared and shared with me by the database officer. I telephoned all interested participants on the list to properly discuss the study and determine their availability and possible time for interview. However, 15 caregivers could not participate in the study due to the following reasons: phones were switched off or not reachable, child was in boarding school, caregiver needed to seek the approval of her husband (which in some cases was not granted), caregiver could not be reached on phone, family had moved to another state, and caregiver did not understand the study. Six out of the nine caregivers who expressed their interest in participating were either not available in the Federal Capital Territory for the interview, declined participation, did not call back to decide on the interview date, or were sick at the time. A total of three caregivers who indicated interest and secured the interest of their daughters were then provided with consent forms and assent forms. Following the triad method of recruitment, the three adolescent girls were approached to provide the names of HCWs who had provided services to them from the health facility. A list of staff providing services to ALHIV at the facility was requested and obtained to confirm and recruit the names of staff provided by the adolescent girls. A total of three staff of the facility were then recruited for the study.

The names of all nine research participants who were recruited for the study (see Tables 2,3 and 4), were de-identified with codes. This code list was kept confidential by me with no one having access to it. Prior to the interview, all shortlisted caregivers were provided with “caregiver consent forms” for the interview of their adolescent girls and “parent consent forms” for their own interviews. Two of the adolescent girls with PHIV between 15-17 years were provided assent forms, while 1 adolescent girl who was above 17 years at the time of the recruitment, was provided with a consent form. The three HCWs were provided “healthcare worker consent forms” prior to their interviews. All research participants were provided the options of a face-to face interview in a secluded and comfortable room at the health facility, a place outside the health facility that was safe and private, or a phone interview. All participants preferred the face-to-face interview in a secluded and comfortable room at the health facility.

All interviews were conducted in compliance with the COVID-19 prevention protocol provided by the government and the health facility, and all interviews used the appropriate interview guide with open-ended questions. To address any psychological risks, a trained adherence counsellor was on standby to address such challenges. All participants were reassured that their identities would not be revealed or mentioned in the study and that they were free to leave the interview at any time without prior notice. All interviews were recorded using an electronic recorder after obtaining permission from the participants and stored in my personal computer for transcription. To elicit very rich information from the experience of all the participants, I used open-ended questions for the interview and probed further in some questions to have a proper understanding of the responses of each participant. This method was helpful in keeping the participants engaged and created opportunities for them to reflect on their past and present experience based on the questions asked.

Five of the interview sessions lasted an hour while four lasted slightly above an hour. All the adolescent girls comfortably shared their experiences except one who was tearful about a particularly sensitive question. With her permission, I sought for the assistance of the adherence counsellor who promised to address the issue with the adolescent girl.

The timing of the interviews was when the girls were on their second term holiday from school, and all the interviews were conducted within four days. All the caregivers accompanied their girls to the health facility for the interview but stayed away from the interview room and session. I ensured the timing for the HCWs interview did not interfere with their official duties.

Variation in Data Collection

The initial research design approved for this study included adolescent girls with BHIV 15-19 years and their caregivers. However, this was not possible following the first data set generated by the health facility for study. Only one caregiver with adolescent girl who has BHIV was identified from the first data set of potential research participants. I sought for the assistance of the Chair to change the study design to only adolescent girls with PHIV and their caregivers which was granted. The title of the study was also adjusted to reflect the change.

Data Analysis

I carried out the data analysis using Colaizzi's (1978) seven-step method of descriptive phenomenological analysis in which several significant statements and theme clusters were identified and integrated to formulate an exhaustive description that assisted to provide meaning to the phenomenon thoroughly.

Following the verbatim transcription of all electronic data from the semi structured face-to-face interviews conducted for the 3 categories of research participants involving nine persons and interviews, I first familiarized myself with the data. This involved reading through all the rich information provided in the nine transcripts to provide a comprehensive understanding of the material. This was followed by identifying all significant statements made by the participants that are relevant to the phenomenon under study. Meanings relevant to the phenomenon from the significant statements, were then identified. I reflexively provided "brackets" to any pre-suppositions made by me to ensure I stick to the phenomenon as experienced by the participants.

I then coded and categorized the formulated meanings and checked for correctness and consistency of meanings. I then clustered the identified meanings into themes that are common across all accounts ensuring "bracketing" of personal pre-suppositions. I incorporated all the themes initially identified into an exhaustive description of the phenomenon. The exhaustive description which provides the overall structure of the phenomenon was further condensed into a short but dense statement that contains all essential structures of the phenomenon as provided by all the participants in the different categories; adolescent girls with PHIV, their caregivers and HCWs from the health facility. Using “member checking” I presented the condensed statement to all the nine participants separately in their different categories for validation of findings. All participants reported that the findings are true reflection of the experience described by them thus validating the accuracy of my findings. Following the final report from the participants, no further modification was made to the findings.

Evidence of Trustworthiness

The different strategies to ensure trustworthiness as outlined in chapter three were used by me during the study. These includes Credibility, transferability, dependability, and confirmability.

I utilized the process of member checking with the nine participants across the 3 different categories of participants during the second meeting to achieve credibility. Copies of the transcripts from the different interviews and summarized description of the phenomenon were provided to each of the participants for validation. Each participant was asked to read through the transcripts to ascertain that I captured their experiences as shared with me and that the summarized description of their experiences derived from the themes were consistent with their personal experiences of the phenomenon. The feedback from the participants shows that findings are consistent with the lived experiences of the participants with minor corrections which were more about transcription and typographical errors.

I achieved transferability by developing questions from similar research that elicited rich information and attained theme saturation about the lived experiences of adolescent girls living with PHIV during the interview process. I also used probing method to elicit deeper information during the research as suggested by Burkholder et al. (2016). These approaches provided detailed descriptions of the data and context to allow for comparisons with similar context based on the rich information provided (Ravitch & Carl, 2015).

The dependability of the study was achieved by ensuring that all the research processes were properly documented and are available for audit by the Chair and Committee member. Furthermore, I electronically recorded and transcribed all participant interviews which included my thoughts and observations and used hand coding for the data analysis to identify the themes for the study. Thus, readers or researchers who are interested in similar research can depend on this report as a guide.

Finally, confirmability for the study was reached by ensuring that the findings of the study is the true representation of the experiences of the participants and does not include the preferences and characteristics of the researcher (Shenton, 2004). The preferences and characteristics of the researcher was addressed through the process of bracketing during data collection and analysis.

Results

In this section, the data from the three interview types are presented together under each meta-theme, and interpretation in chapter 5 is by research questions & meta-theme.

Table 5

Metathemes, Themes, and Subthemes for Adolescent Girls With PHIV, Caregivers, and Healthcare Workers

Metatheme	Themes	Subtheme
1. KNOWLEDGE OF HIV STATUS OF THE GIRLS	Theme 1: Knowledge of HIV fairly accurate? (RQ1, Girls only)	Subtheme 1.1: Meaning of HIV/AIDS Subtheme 1.2: Knowledge of HIV Transmission Subtheme 1.3: Knowledge of HIV Prevention
	Theme 2: Knowledge of HIV status by AGPHIV. (RQ1, Girls only)	Subtheme 2.1: Knowledge of own HIV status. Subtheme 2.2: Reaction to known HIV status Subtheme 2.3: Parents' advice to AGPHIV after known HIV status
2. DISCLOSURE	Theme 3: Disclosure of HIV status by AGPHIV. (RQ1, Girls only)	Subtheme 3.1: Disclosure to family members Subtheme 3.2: Disclosure to friends Subtheme 3.3: Reason for disclosure to friends. Subtheme 3.4: Post disclosure reactions.
	Theme 4: HIV status disclosure. (RQ2, Caregivers only)	Subtheme 4.1: Unpleasant experience of caregivers before knowledge of HIV status of their adolescent girls. Subtheme 4.2: HIV status disclosure to child by caregivers Subtheme 4.3: Knowledge of own HIV status of caregivers.
	Theme 5: Disclosure of HIV status of ALPHIV. (RQ3, Healthcare workers only)	Subtheme 5.1: The different types of HIV status Disclosure. Subtheme 5.2: Factors to consider before disclosure to ALPHIV. Subtheme 5.3: Challenges with HIV status disclosure to ALHIV. Subtheme 5.4: ALPHIV reactions after HIV status disclosure Subtheme 5.5: Healthcare workers and ALPHIV disclosure preferences. Subtheme 5.6: Curiosity of ALHIV towards disclosure of HIV status.
3. ANTIRETROVIRAL THERAPY (ART)	Theme 6: Access to ART for AGPHIV. (RQ1, Girls only)	Subtheme 6.1: First time knowledge and experience with ARV. Subthem 6.2: Years of exposure of AGPHIV to ARV Subtheme 6.3: Reasons for adherence to medication Subtheme 6.4: Challenges faced by adolescent girls with PHIV, with ARV Subtheme 6.5: Challenges with missed medication/non-adherence Subtheme 6.6: Reasons for missed drug/non-adherence Subtheme 6.7: Personal strategies of adolescent girls with PHIV for adherence to medication
	Theme 7: Concerns of the girls on long-term use of ARV. (RQ1, Girls only)	
	Theme 8: Adherence to medication. (RQ2, Caregivers only)	Subtheme 8.1: Adherence strategies of caregivers and their adolescent girls. Subtheme 8.2: Adherence to medication challenges at child's boarding school
	Theme 9: Antiretroviral treatment for AGPHIV. (RQ3, Healthcare workers only)	Subtheme 9.1: Drug Regimens for ALHIV. Subtheme 9.2: Pills fatigue experience of ALPHIV. Subtheme 9.3: Reduced Adverse Drug Reactions (ADRs). Subtheme 9.4: Treatment of adverse drug reactions by HCWs.

Metatheme	Themes	Subtheme
	Theme 10: Common health problems associated with ALPHIV. (RQ3, Healthcare workers only)	
	Theme 11: Promoting adherence to ART among AGPHIV. (RQ3, Healthcare workers only)	Subtheme 11.1: The “Activists” as role models for ALPHIV. Subtheme 11.2: Factors that promotes good adherence Subtheme 11.3: Promoting adherence during COVID-19 lockdown.
	Theme 12: Reasons for non-adherence among AGPHIV. (RQ3, Healthcare workers only)	Subtheme 12.1: ALPHIV medication pranks. Subtheme 12.2: Unsupervised ALPHIV medication intake by caregivers. Subtheme 12.3: Poor-adherence by maternal and paternal orphans Subtheme 12.4: The difficulty of adherence in a boarding school set-up.
	Theme 13: Addressing the challenges of non-adherence to ART. (RQ3, Healthcare workers only)	Subtheme 13.1: Adherence class for non-adhering ALPHIV. Subtheme 13.2: Viral Load Assessment to check for AGPHIV non-adherence Subtheme 13.3: Direct Observation Therapy as a strategy to address nonadherence. Subtheme 13.4: Pill counting as strategy to check for non-adherence. Subtheme 13.5: Addressing opportunistic Infections among AGPHIV. Subtheme 13.6: Caregivers escort support to ALPHIV.
4. EVERYDAY LIFE	Theme 14: Girls everyday life experience. (RQ1 Girls only)	Subtheme 14.1: Access to daily needs for adolescent girls with PHIV. Subtheme 14.2: Peculiar challenges of AGPHIV. Subtheme 14.3: A parent’s highhandedness towards his AGPHIV. Subtheme 14.4: Household Economic challenges faced by the girls. Subtheme 14.5: Relational life of AGPHIV.
	Theme 15: Caregivers challenges with managing child’s condition. (RQ2 Caregivers only)	Subtheme 15.1: Difficulties of caregivers in managing the health condition of the girls Subtheme15.2: Caregivers experience with girls' non-adherence. Subtheme 15.3: Caregivers advice to girls on relationship and sex. Subtheme 15.4: Addressing menstrual hygiene of the girls Subtheme 15.5: Activities for daily living (ADL) of AGPHIV.
	Theme 16: Household needs of caregivers of AGPHIV. (RQ2 Caregivers only)	Subtheme 16.1: Caregivers Household Economic needs. Subtheme 16.2: Transport support need for clinic visits by the girls. Subtheme 16.3: External support provided to households of AGPHIV.
5. STIGMA	Theme 17: Stigma and Discrimination experience by AGPHIV. (RQ1, Girls only)	Subtheme 17.1: Experience of stigma and discrimination by AGPHIV Subtheme 17.2: Self-stigma experience of AGPHIV. Subtheme 17.3: Community perception of PLHIV by the girls.
	Theme 18: Stigma and Discrimination experience of caregivers. (RQ2 Caregivers only)	Subtheme 18.1: Experience of stigma from family members. Subtheme 18.2: The challenge of self-stigma. Subtheme 18.3: Community perception of PLHIV by the caregivers.
	Theme 19: Addressing stigma against ALHIV in the health facility. (RQ3, Healthcare workers only)	

Metatheme	Themes	Subtheme
6. SUPPORT	Theme 20: Support System for AGPHIV. (RQ1, Girls only)	Subthemes 20.1: Varying support system for AGPIV. Subtheme 20.2: Support group as a good resource center for AGPHIV.
	Theme 21: Adolescent Support Group at health facility. (RQ3, Healthcare workers only)	Subtheme 21.1: Adolescent support group meetings at the health facility. Subtheme 21.2: Support group composition and "atmosphere." Subtheme 21.3: Advantages of ALPHIV attending the Support Group meeting. Subtheme 21.4: Structured OTZ Adolescent Support Group
	Theme 22: Support System at the health facility for AGPHIV. (RQ3, Healthcare workers only).	Subtheme 22.1: Support for Indigent ALHIV Subtheme 22.2: Food support provided by the health facility to AGPHIV Subtheme 22.3: External Support to health facility.
7. HEALTH SERVICES	Theme 23: HIV/AIDS service delivery at the health facility. (RQ3, Healthcare workers only)	Subtheme 23.1: Free HIV services provided to ALHIV Subtheme 23:2: Types of Services provided to ALHIV at health facility. Subtheme 23.3: Differentiated Model of Care; multi month scripting. Subtheme 23.4: Inter-facility Relationship with other the health facilities.
	Theme 24: The Girls' Experience with Health services. (RQ1, Girls only)	Subtheme 24.1: First time experience at health facility. Subtheme 24.2: Longer term experience at facility Subtheme 24.3: Frequency and reasons for visits.
	Theme 25: Caregivers Experience with health services. (RQ2, Caregivers only)	*No Subthemes here as the main theme is unique to the caregivers' experience about the health services provided by the health facility.*
	Theme 26: Caregivers' account of support provided by health facility. (RQ2, Caregivers only)	*Same as above*
	Theme 27: HealthCare Delivery at health facility. (RQ3, Healthcare workers only)	Subtheme 27.1: Family centered model of care. Subtheme 27.2: Transition of ALPHIV to Adult Care
	Theme 28: Challenges faced by HCWs in providing services to AGPHIV. (RQ3, Healthcare workers only)	Subtheme 28.1: Barriers to service delivery. Subtheme 28.2: Financial challenges of Health Facility. Subtheme 28.3: Missed appointments & lost to follow-up at health facility. Subtheme 28.4: How the health facility addresses missed appointments and lost-to-follow-up. Subtheme 28.5: Lack of Reproductive Health Services for AGPHIV.
	Theme 29: Recommendations for service delivery. (RQ1, RQ2 & RQ3, Girls, Caregivers and Healthcare workers	Subtheme 29.1: Recommendations for improved service delivery by the girls. Subtheme 29.2: Recommendations for improved service delivery by the caregivers. Subtheme 29.3: Recommendations for improved service delivery by the healthcare workers.

Data for Metatheme 1: Knowledge of HIV Status of the Girls

Theme 1: Knowledge of HIV Fairly Accurate

All three girls showed a fairly accurate good understanding about the meaning, prevention, and transmission of HV to the best of their knowledge.

Subtheme 1.1: Meaning of HIV/AIDS

All the girls provided the meaning of HIV/AIDS but were not able to articulate their words accurately. For example, one girl said it was “The Human Immune Disease,” another called it the “human immune virus,” and a third “Efficiency Deficiency Virus syndrome.”

Subtheme 1.2: Knowledge of HIV Transmission

All three girls were clear about fluid exchange as the way in which HIV is passed from one person to another. For example, one girl stated transmission occurred “through sex, through transfer of blood or through parents … or by breastfeeding or by giving birth.” Another noted transmission occurred by “sex with an infected person … or the baby can contact it through breast feeding.” There was also some understanding of the role of shared objects, though this was far from clear: one girl said transmission could occur through “sharing of sharp objects,” while another referred to “using sharp objects, or using a toothbrush with someone, [or] when the nipple of the mother has a wound and she is positive."

Subtheme 1.3: Knowledge of HIV Prevention

The three girls in my sample provided varying information on how HIV can be prevented. Common was the felt need to avoid the use (or sharing?) of sharp objects and keeping them safe from others. One of the girls also indicated the need for blood screening before transfusions, while another talked about avoiding sex as an adolescent, and reported the need to avoid the sharing of toothbrushes. A typical quote for these issues was, “HIV can be prevented by … avoiding sharing of sharp objects with someone who has HIV, and through childbirth; mothers should make sure they treat themselves and seek the doctors advise". Interestingly, two of the three girls spoke of the need to stay healthy to prevent HIV infection. One said, “HIV can be prevented by taking good care of yourself” and another said, “You can prevent it by eating well (and) living in a clean environment".

Theme 2: Knowledge of HIV Status by AGPHIV

All the girls discussed the different circumstances that led to them knowing their HIV status as disclosed by their parents. Knowledge of HIV status emerged as a very important theme in understanding the lives of adolescent girls living with perinatal HIV.

Subtheme 2.1: Knowledge of own HIV status

All the three adolescent girls indicated that they were aware of their HIV status because their parents disclosed it to them. One of the girls indicated that "My daddy asked me if I knew why I was always coming to the hospital? And I said NO. He then told me I am HIV positive." Another girl informed that “My mother told me when I was a child that I am HIV positive when she discovered her status”. The third narrated how she got to know: "I was very ill and so my dad and mum took me to my granddad (father to my mum). That’s how they discovered I have HIV and then brought me to XXX."

When asked when their status was disclosed to them, two of the adolescent girls said they did not know, however, one of them indicated that “I was seven years when she told me that I have the sickness”.

Subtheme 2.2: Reaction to known HIV status

The three girls expressed their feelings and thoughts after knowing their HIV status. While one of the girls accepted her status without any hard feelings, another girl said she did not comprehend “Because I was just a child when my mum told me about it, I did not know anything. However, as she grew, she felt isolated because of the drug she was taking: “I started feeling that other people are living in good health and I am the only person taking this drug”. The third girl (AG3) was worried: “I felt bad and very worried, worried as in “how did I get it?”, and “why is it that it was me that got it?”. She inquired from her father who misinformed her she was infected through blood transfusion: "I even asked my dad too, but he told me that when I was sick, they had to transfuse blood in me. That’s how I got the HIV" which she later discovered from her mother was not correct:

> Yes (they told me it was through blood transfusion), but later, I still asked my mum. She said, to be sincere with me, she did not know how I got it and how she got it too. When she got married to my dad, they did not do any test together. She was the only one that did the test and so she doesn’t know if it’s from her or from my dad.

Data for Metatheme 2: Disclosure

Theme 3: Disclosure of HIV Status by AGPHIV

Disclosure of the HIV status of all three girls to persons within and outside the family emerged as one of the major themes in the study.

Subtheme 3.1: Disclosure to family members

When asked if they have disclosed their HIV status to other family members, one of the girls informed that "As we continued to visit the Clinic for our meeting and they discuss about HIV, that's how they (siblings) knew". Another girl indicated that: "recently my mum told her senior sister " while another girl indicated that: "already, my granddad knew about it, my aunties and some of my aunties and some of my uncles."

Subtheme 3.2: Disclosure to friends

All the girls informed that their parents asked them to keep their HIV status secret however, one of the girls indicated that her mother disclosed her HIV status to her childhood friend without her consent although she was not comfortable with it because she feared that her friend might use it against her in the future: "my mum disclosed my HIV status to my childhood friend. I asked her why she did that. I don't want anybody to use it to intimidate me." Despite her parent's instruction not to disclose to anyone, one of the girls disclosed her HIV status to one of her friends and gave the reason:

> I only told one of my friends…. if she is truly my friend, she shouldn't tell anyone what I was going to tell her…… due to what my dad told me and every time I tell her I am going to the hospital for check-up, she gets

> worried and would always ask why I regularly go for check-up? I told her
> I will tell her one day. So, I decided to tell her."

Subtheme 3.4: Post disclosure reactions

Following the disclosure of their HIV status to some of their friends and family members, there were mixed reactions from two of the girls. While one felt bad because her mother did not seek her consent before disclosing to her friend, another said: "I feel free" …., and that her friend "still maintains closeness ……. She was very sad and she pitied me".

Theme 4: HIV Status Disclosure

In this study, HIV status disclosure emerged as a fundamental theme that provides information on the experience of the caregivers of adolescent girls living with perinatal HIV prior to the knowledge of the HIV status of their daughters and after.

Subtheme 4.1: Unpleasant experience of caregivers before knowledge of HIV status of their adolescent girls

Describing their individual experience prior to knowing the HIV status of their daughters, a caregiver said: "I was always with hospital file running from one place to the other in the hospital because my child had several illnesses, and I was always lying and couldn't live free. so, I was tired of life." She also narrated: "At a particular time, it was sickness from one year to the other up till seven years." Another caregiver narrated how her daughter was transfused with blood because she was anemic:

> When I gave birth to my daughter, she became very sick, and I then took her to the hospital. We were told that she was short of blood and so blood was donated, and she was transfused but the sickness did not stop.

However, her condition did not improve: “The sickness became severe and so I had to tell my father who asked me to bring the child home”. Her daughter was tested of HIV at the request of her father: “the child was taken to the hospital and HIV test was conducted on her. The result came out positive and that’s how I knew about her status.”

She further narrated her ordeal: “when I got to know that it is HIV, I was completely down but my husband encouraged me”.

Subtheme 4.2: HIV status disclosure to child by caregivers

A caregiver informed that her husband was the one who disclosed to their daughter: “The dad tried to explain to her why she was constantly coming to the clinic and why she’s using the drug because she is infected with the virus called HIV “ and how she further supported the process at home: “When she got home, I also tried to shed more light on how it happened. That was how she got to know her status”. She further narrated how difficult it was for her to disclose to her daughter before the husband did: “I don’t even know where or how I was going to tell her because I realized the mistake on my own part as a parent.”. She took responsibility for infecting the daughter: “I failed and that was why she is infected”.

Another caregiver narrated how she disclosed to her daughter: “She was either 8 or 10 years and was not on drugs (medications)……I had to let her know even though as a mother, I hardly knew about HIV/AIDS which was rampant in 2003.”. She further narrated: “she did not know what I was telling her, but I still told her any way. She informed that because they are both friends, it was not difficult for her to disclose to her daughter: “It was not difficult because we started the clinic together, I go everywhere with her, collect drugs with her. Disclosing it was no more a problem because it was as if it was two of us leaving alone”.

Caregiver CG3 informed that the HIV status of her daughter was disclosed to her by her and her husband after conducting HIV confirmatory test in the health facility: We returned to Abuja and went to XXX where another test was conducted and found to be positive; After this, we called her and told her about her status. She felt bad but we spoke very well with her and so she calmed down.”

She further narrated how difficult it was for her to disclose to her daughter:

> For me it was difficult, but I had no other choice. I thought of keeping it from her but decided to tell her because since she’s my daughter, and from the pills she’s been taking, I know one day she will ask me, and I might not know what to tell her.

Subtheme 4.3: Knowledge of own HIV status of caregivers

A caregiver narrated how she got to know her HIV status after her third child who was frequenting the hospital more often because of illness was tested and confirmed to be HIV positive: “No, the third child. So, he’s been in and out of the hospital…. So, I had to be tested and the other children too. So that was how we got to know our status. Another caregiver narrated that she was ignorant of the virus when her daughter was often sick:” I did not really know about it”, and when she knew, she was placed on drugs: “When I got to know and was placed on drugs, there were so many issues that was happening that affected my daughter getting to know about it.”. The third caregiver informed that she got to know her HIV status after discovering the daughter’s status and that it was not through blood transfusion as earlier thought:

> it was through my daughter when she was sick. I did not know I had the same problem so one day when I brought her for her medication, I decided to do the HIV test. It was when the test result was released that I realized my status and that my daughter got it from me. Formerly, I thought she got it from the blood transfusion that was conducted on her some years ago.

Theme 5: Disclosure of HIV Status of ALPHIV

In this study, HIV status disclosure emerged as a strong theme across the three healthcare workers who provide services to these adolescent girls living with perinatal HIV. The subthemes below provide a broad understanding of this theme from the experience of the healthcare workers working with ALPHIV and their caregivers.

Subtheme 5.1: The different types of HIV status Disclosure

A HCW informed that the health facility provides partial and full disclosure to adolescents living with HIV:

> Disclosure is done around the ages 14, 15, 16, 17 years range. For children that are younger than that, what we have is partial disclosure. At that point, we have full disclosure when they are in senior classes in secondary school.

The HCW also described the reasons for full disclosure; “for the benefit of their health, some of them at that point, they will be going to boarding schools and so we need to let them know.” The same HCW described accidental disclosure: “we realize that a lot of them got to know their status accidentally; not guided. Some got to know their status in the course of coming for routine clinic visits and in the process of giving health talk.”

He also described another scenario for accidental disclosure:

> Another scenario is that you meet an adolescent and ask, “how did you know your status?”. They will respond with “oh, I overheard my mum discussing with my dad or discussing with somebody. They mentioned my name and then mentioned HIV and from there I knew.

Another HCW describe another type of HIV disclosure, the caregiver-assisted disclosure: “The HCWs sometimes accompany the caregivers and provide some assistance to the caregiver on how to disclose to the child or may help to facilitate the disclosure between the mother and the child.”

Subtheme 5.2: Factors to consider before disclosure to ALPHIV

Two out of the three HCWs informed on the importance of getting consent from a caregiver/parent before commencing a disclosure process: “We do not have many challenges with disclosure as long has the caregivers gives consent.” However, some caregivers: “decline consent and so we can’t go ahead with disclosure for the adolescent…in doing this disclosure, we need the consent of the caregiver”. Another factor to consider before disclosing HIV status to adolescents living with HIV is the cognitive development of the adolescent as indicated by two of the three HCWs in the study: “This child’s cognitive development is very low otherwise another adolescent his age would have known his status by now without the mother disclosing it.”; “he or she will know their status especially if their cognitive development is high.”

A HCW indicated that the personality of the adolescent is also important when planning to conduct HIV status disclosure:

> Truly, we have some children who are sanguine; they can talk. When you disclose, you must look at the personality of the child. If the child is a talkative, you will have to be careful what you say to that child.

Another HCW also included the capacity of the healthcare worker as one of the factors to be considered when planning on HIV status disclosure: “On the part of the health care worker, some are not trained and are not capable of handling this part (disclosure)…….Initially, (disclosure) capacity was an issue, but we were able to succumb that.”

Subtheme 5.3: Challenges with HIV status disclosure to ALHIV

The refusal to give consent for HIV status disclosure was described as a major challenge by one of the HCWs:

> the major problem we have with this group of people is that the parents do not like disclosing to them (adolescents). We have an adolescent who visited the facility today. He is 16 years plus; the mother requested that we should not disclose the child’s status to him.

The HCW also gave the reason for the parents' refusal to disclose to their children: "These parents have self-stigma and are afraid of being stigmatized…. they feel that the child may disclose his/her status in public?"

Another HCW indicated that: "Some caregivers are hiding their status from their children who may already have known about HIV from their school or studies, or already have known their status".

One of the HCWs indicated the fear of uncertainty on their part of the caregiver as a challenge: "On the part of adolescents and caregivers, there was fear of uncertainty; what will happen, how will this child respond and the issue of confidentiality on the part of the adolescent. The HCW also informed that: "Some of the caregiver feel their adolescents (kids) are not matured enough."

Subtheme 5.4: ALPHIV reactions after HIV status disclosure

A HCW informed on post disclosure outcomes of adolescents living with:

> Many of them, when they get to know their status, are depressed, traumatized, they are not happy with it, a lot of thoughts go through their minds, and they ask questions. They don't ask us some of those questions directly. ………. Some of them ask "ok, how did I get this HIV…. and the caregiver find it difficult to provide an answer and so they come to ask us.

The HCW also indicated:

> That period of depression or trauma will last for 2 to 3 years and then the child comes to accept full responsibility to take the ARV even though a

> good number of them are still not happy with it, they eventually come to accept the reality on ground and begin to take their ARV.

Another HCW informed on some secret activities of these adolescents: “Some have gone secretly to do HIV test just to confirm what they heard from their caregiver or from the hospital regarding their status since they are not actually feeling sick.”

A HCW informed that the girls do not give many challenges when disclosed to when compared to the boys: “We do not have any girl child in this kind of situation; mothers have a way of pampering their children when they know they’re guilty.” Another HCW also indicated that some reactions from some of the adolescents may be violent: “The experience we have is the one that clashed with the parent to the extent that the parent ran to the counsellor who tried to help.”

Subtheme 5.5: Healthcare workers and the girls disclosure preferences

A HCW indicated their disclosure preference: “We prefer the caregivers to disclose to their children. We only come in fully when the child refuses to take the drug or when the caregiver indicates that he/she cannot disclose to the child.”. One of the HCWs indicated the disclosure preference of adolescent girls: “they will prefer that the caregivers disclose to them and not the HCWs based on their age.”

Subtheme 5.6: Curiosity of ALHIV towards disclosure of HIV status

A HCWs described how curious the ALPHIV are to know the reasons behind the drug they have been taking for years: “I asked him how he knew he is HIV positive, he responded by saying “since my mum refused to tell me, I googled it online. I picked the name of the drug and checked online. That’s how I knew.” However, another HCW also indicated some actions taken by some caregivers to address the curiosity of their adolescents: “so many of the caregivers keep those drugs away from them and only bring them out when they want to administer the drugs.”

Data for Metatheme 3: Antiretroviral Therapy

Theme 6: Access to ART for AGPHIV

As adolescent girls living with perinatal HIV, all the three girls described their long-term experience on ART for many years, the reasons they adhere or do not adhere to their medication and the challenges they face when with their medication.

Subtheme 6.1: First time knowledge and experience with ARV

The three girls had been on ARV and were not told until their HIV status was revealed to them by their parents. All three participants informed that they did not know the name of the drugs prescribed for them by the doctors which they have been taking for some years but simply call them “HIV drugs”: "I don't know about medications prescribed for me” and “The only medicine the pharmacy gives me is the HIV medicine.”

One of the girls described her experience taking the drug and her fear of death: "When I started taking the drugs and I was not comfortable taking the drugs. He (dad) asked me to take it otherwise I will lose my life. So, I got scared and continued taking it." She further indicated: "It was because, it was something new and something I have never done before. So, I was asking “why are am I taking these drugs and what is the illness in me that is making me take these drugs?"

Subtheme 6.2: Years of exposure of AGPHIV to ARV

All the three participants indicated the number of years they have been on ARV. One of the girls said, “I don’t know the exact date, but my mum said since I was five (5) years old” while another said "yes, for over 7 years because I can remember when I was 10 years, I was still taking the drug". The third girl said: "I started taking the drugs from 2010."

Subtheme 6.3: Reasons for adherence to medication

In this study, adherence to treatment emerged as a major factor for viral load suppression and healthy living. All the three girls provided their individual reasons for adhering to treatment from the experience of living with the virus for many years. One of the girl’s main reasons for adhering to treatment is: “To have a low viral load and to reduce the HIV in our body so we can live healthy.” Another girl indicated that her reason: “so that the drugs can fight the virus… you have to take the drugs so that the white blood cells can be strong.” Another girl gave her reason:

> It’s because of what my daddy told me that I should be taking the drugs if not, I will lose my life. They then asked me to attend the support group meeting where they repeat the same thing; that I should be taking my drugs.

One of the girls shared her experience when she initially stopped taking her drug and the fear of dying by AIDS:

> When I came back to the hospital, the doctor told me that if I don’t take my drugs well and it gets to AIDS, I will die. So, all those experiences made me sit up to take my drugs at the right time, do the right things,

> come to the hospital, listen to what my doctors tell me and also come for support group meetings.

Subtheme 6.4: Challenges faced by adolescent girls with PHIV, with ARV

Two of the girls informed that they do not have any challenges with taking the ARV: “NO, I don’t feel anything when I use the drugs.”; “Presently I do not have any challenge”, However, one of the girls indicated her challenges: “but because of not having enough food to eat which helps the drug to work faster, whenever I sit down for a long time and get up to do something, I start feeling dizzy”. She also complained that the drug makes her hungry: “the drug use to make one hungry”. The third girl also said: “The first time I started taking the drug, I feel dizzy. It will make me eat. The drug makes me sleep deep in the night”. She however, said: “The dizziness and weakness happened when I don’t eat well (and I take the drugs) but when I eat well it doesn’t happen.”

Subtheme 6.5: Challenges with missed medication/non-adherence

When asked about their experience with missed drugs, one of the girls indicated: “No, I also take the drugs. I do not miss.” Another girl indicated that while in a boarding school, she stopped taking her drugs: "because of my friends. They wanted to know why I was taking it (drugs)? And I didn’t want them to know about it". She also indicated that:

> I stopped taking my drugs for some time. I was feeling okay the way normal people feel, I was not feeling anything……… the doctors scolded me for not taking the drugs and threatened that if I continue not taking the drugs, they will bring me to the hospital, put me on bed and force me to take the drugs (smiling).

Subtheme 6.6: Reasons for missed drug/non-adherence

One of the girls with the boarding school experience, informed: "I found it difficult because of the distance of my class to the sickbay; trekking to the place and coming back. I found it difficult to go there so I just sit down and forget about the drugs.". Another girl explained her reason for missing her drug: "that was early last year when my daddy was having challenges with his business (financial challenge). I was not able to come to the clinic to pick my drugs."

Subtheme 6.7: Personal strategies for adherence to medication

In this study, the girls developed strategies of ensuring they adhere to treatment as prescribed by the doctors at the health facility. Adherence strategy therefore emerged as a strong theme indicating how these participants followed through with their treatment.

To ensure she does not miss her drug pick-up/refill appointments, a girl indicated: “It is my mummy that comes to pick up the drugs for us.” She also informed that: “we take our drugs at the same time. Me, my brother, and my mummy…… She sets an alarm for taking the drugs.”; "I take my drugs (in the morning) before I go to school".

Another girl narrated what she experienced when she was in a boarding school: “my mum does collect my medication and when she’s coming for my visiting (in boarding school), she will drop the drugs with the senior nurse”. To adhere to her medication, she said: “I have my wristwatch and so once it is 7 pm, I go to the sickbay to take my drugs and I then return for my prep”. However, since she left the boarding school, the story is not the same:

> I do come to pick my drug and keep it in my wardrobe. I take my drug at the same time with my mum at 7 pm…. I have a small phone which I use to set an alarm. Once the alarm rings, I quietly go to take my drugs and then take water.

The third girl gave the reason her mother picks her drugs for her: “yes, during the exam period or when she is less busy.” She also indicated her personal adherence strategy: “Sometimes I get reminded when it’s getting dark (night), sometimes when the Muslims call for their evening prayers”.

Theme 7 Concerns of the Girls on Long-Term Use of ARV

The girls’ were asked their thoughts on long-term experience with ARV: “I know that as I continue taking this drug, when I give birth, majority of my kids will not have the disease. I will continue taking it to prevent anybody close to me from having it.” Another girl indicated that:

> Living with ART for so many years; I don’t really feel any regrets taking the drugs or living with it because, I gain advise from my mum and from the hospital”; “The support group has been a big helping hand to me.
>
> The third girl narrated her experience and her fear of developing AIDS:
>
> I was having that thought and so I asked myself “when would I stop taking the drugs…….When would I stop coming here?”. But coming to the support group meeting, we were told that if we stop taking the drugs, the virus will increase, and the drugs will stop working and then we enter second line and then it gets worse to AIDS. From there, I tell myself,

> instead of stopping this drug and then get to AIDS, I will continue taking it.

Theme 8: Adherence to Medication

In this study, adherence to medication emerged strong as a pre-condition for healthy living by caregivers and their adolescent daughters living with perinatal HIV. The different subthemes provide valuable information about the adherence experience of the participants.

Subtheme 8.1: Adherence strategies of caregivers and their adolescent girls

The caregivers described the different strategies adopted by them and their daughters to ensure adherence to their medication. A caregiver shared her experience: "I told her, once you stop this drug you will be very sick, and you will die, and you will not like the way you will look before your death." She also indicated the adherence strategy she and her daughter adopted:

> we set an alarm. She's there to take her medication. It is much easier now because it is once in a day because when it was twice (we take morning and night); she will come and whisper to me that it's time to take the drug, and that she has taken her drug.

The same caregiver (CG2) described how her daughter had been missing her drug and what helped her to adhere:

> She was more interested in watching the video they play when she visits the hospital. The video was about HIV and how it works in the body …

> those videos helped both of us because it also relieved me of the stress of her taking her drugs.

She also informed that she and her daughter support themselves in taking their medication: “We help ourselves in taking the drugs. If we are going out together to do our casual job, and I forget to take the drugs, she will laugh and say that she has picked the drugs already.”

The caregiver (CG3) described how her husband supports their daughter:

> her dad bought her a small mobile phone and set the alarm at 7 am for her to take her drug. Sometimes when the father is not at home, he sometime calls to remind us to take our drugs when it gets to the time.

Subtheme 8.2: Adherence to medication challenges at child’s boarding school

One of the mothers described the adherence challenge her daughter faced at the boarding school as a student.:

> She shared her experience of how friends in school were also worried about her going to the clinic every day to take her drugs. They were interested in the type of drug she was taking. She said she will sometimes skip taking the drugs until when the friends are not with her. As a result, the nurse at the clinic will get angry with her for missing her drugs. Sometimes she will intentionally miss taking her drug since her friends claimed she was taking the drugs every day. She will want to prove to them that she doesn’t take the drugs every day.

The caregiver therefore indicated that: When they advised me at the health facility, I decided to bring her back from the boarding school."

Theme 9: Antiretroviral Treatment for AGPHIV

In the study, antiretroviral treatment emerged as a theme which describes treatment management among adolescent girls living with perinatal HIV from the viewpoint of the healthcare workers who provide services to them. The subtheme below provides broad information about this theme.

Subtheme 9.1: Drug Regimens for ALHIV

HCW3 indicated that the health facility provides once-a-day and twice-a-day regimens for adolescents living with HIV:

> From childhood, drug regimen tends to be twice in a day in general but as they grow older, we are able to find regimen that can be taken once a day. For example, when they cross 30kg, we have been able to find regimen they can take once a day which they prefer.
>
> He further described the reason the adolescents prefer the once-a-day regimen:
>
> Sometimes those twice regimen interfere with their school; a child taking a regimen at 6 am will have to take the second at 6 pm. It is difficult because sometimes the child is not at home at 6 pm. So, we tend to favor the regimen that is once in a day.

Another HCW also indicated that the once-a-day regimen is preferred than the twice-a-day regimen where a caregiver might not be available to supervise or assist to administer the drug in any of the times scheduled;

> If you choose a regimen of twice in a day, there might not be someone to supervise in one of those times; the parent may be available in the morning but may not be available in the evening or may be available in the evening but not available in the morning. So, we tend to favor once a day regimen.

HCW3 indicated another type of regimen for ALHIV:

> many of them are on second line because children (in those days) who were diagnosed positive were automatically placed on second line. We have phased out the issue of first line in children some years ago so every child who is diagnosed positive is placed on second line regimen and have grown with that regimen and are now adults.

He also informed that: “those who are perinatally infected and probably diagnosed when they were 10 years old or eight years old, we still find first line drugs for some of them and that is what they are still using till date.”

Subtheme 9.2: Pills fatigue experience of ALPHIV

Two of the HCWs indicated that some these ALPHIV informed that they are tired of taking the drug. One said: “They have issues with adherence. These children will not want to take their drugs. It’s like pill burden; they are tired.” The other reported: “When you ask them, they say they are tired of taking the drug.”

Subtheme 9.3: Reduced Adverse Drug Reactions (ADRs)

Two of the HCWs informed that:

> we rarely have adverse reactions" (HCW1); "Adverse drug reaction is not very common among adolescents." (HCW2) because "these drugs were started in childhood and so the best regimen has been selected for them over this period of time. Hence, by the time they are adolescents we don't have these challenges (HCW3).

However, if adverse drug reactions occur, the clinicians will "have to change the regimen; pull out the offending drug and replace it with a better regimen that is not likely to cause the same problem" (HCW3).

A HCW indicated another possible reason for the adverse side effect such as those cause by the drug-Nevirapine:

> A number of times the doses are excessive and so we have to bring down the dose. I think I can remember one (occurrence) and that was about four or five years ago, and it was drug induced hepatitis caused by Nevirapine.
>
> Also:
>
> Many of them had abandoned their ARV due to side effects once they cannot cope with them especially when we were providing efavirenz which causes nightmares." However, "Depending on the body system, some start showing adverse reaction after two weeks or a week.

Subtheme 9.4: Treatment of adverse drug reactions by HCWs

One of the HCWs indicated how the side effects are addressed: "Once anyone is placed on treatment (ART) we immediately commence home visits/follow-up to address any side effects of the drugs.”. She also indicated that “any drug reaction that has existed for more than four days we bring such a person to the doctors for treatment.”

Theme 10: Common Health Problems Associated With ALPHIV

In this study, the three HCWs listed some health challenges associated with these adolescents living with HIV. Health problems associated with ALPHIV therefore emerged as one of the major concerns identified amongst ALPHIV.

A HCW listed the health challenges identified among ALPHIV as: “malnutrition is common among them”; “… body rashes, diarrhea, malaria and typhoid are the most common. The HCW also indicated that: “Other health challenges occur when there is immunological failure which give rise to other big diseases.” Another HCW also listed “Malaria, toilet infection especially those in boarding schools. Some have diarrhea as a result of the water they take. Cough affects some of the little ones”. HCW3 included:

> For the adolescents we commonly find skin infection called Papular pruritic eruption. The other thing we find occasionally is recurrent vaginal candidiasis. Rarely we have pulmonary Tuberculosis… in the older group you may have chronic diarrhea as a result of some of the second line regimen we are using.

HCW3 also indicated that “Their treatment has been optimum right from childhood and so they grow up healthy most of the time.” However, another HCW included the effect of Nevirapine on some of these adolescents:

> Some of the things you could find includes drug induced hepatitis which was common when we were using Nevirapine as part of our regimen;

> nevirapine with somewhat high CD4 count especially in girls. You could find a few of that.

The rare skin eruption could also be due to Nevirapine containing regimen as indicated by another HCW: “Sometimes you could find skin eruptions but not a severe one, just minor and still limited to nevirapine containing regimen.”

Theme 11: Promoting Adherence to ART Among AGPHIV

In the study, the healthcare workers presented their experience on ALPHIV adherence to their drugs and the different ways the health facility has assisted to make this seamless for them and the challenges encountered. These are discussed via the different Subthemes.

Subtheme 11.1: The “Activists” as role models for ALPHIV

Two of the HCWs interviewed, described themselves as “Activists”-role models to support adherence among ALPHIV: “I’m an activist and a role model, so they have to first see me (as one of them) before they can open themselves or what they think about the virus to me”. The other HCW also said: “we have home based team that is (called) “activist” who visit their homes to encourage them.” This includes encouraging them to adhere to their drugs and treatment using themselves as examples:

> They are PLHIV. They call them activists; they do home visits; they use themselves as examples; if an adolescent is not adhering, they use themselves as examples to say if they were not adhering (to their medication), they wouldn’t look the way they look now.

Subtheme 11.2: Factors that promotes good adherence

One of the HCWs intimated that “Those who have both parents alive and are positive, their adherence is better.” While another indicated that: “For those who are fully aware (of their status), they tend to comply with their medication.”

Subtheme 11.3: Promoting adherence during COVID-19 lockdown

When asked how the health facility ensured the AGPHIV adhered to their medication during the COVID-19 lockdown in the country, a HCW indicated that: “those who were able to come to the health facility to pick-up their drugs did so”. She also described the strategy employed by the facility: “We called the adolescents and asked them to go pick-up drugs at near-by centers.” Where an adolescent was not comfortable with the plan to access drugs from a near-by facility, the health facility provided another option: “It happened to one adolescent……. We linked her up with another center, but she was not comfortable because her mother likes confidentiality. We had to look for someone in that facility to smuggle the drug to her.”

Some of the adolescents travelled out of the state and did not return: “Some who travelled and got stuck (during the lockdown), we called and linked them to other facilities for treatment.”

Theme 12: Reasons for Nonadherence Among AGPHIV

In the study, the three HCWs identified the various reasons some ALPHIV do not adhere to medication. The subthemes below provide a broad understanding of the theme.

Subtheme 12.1: ALPHIV medication pranks

One of the HCWs described her experience with ALHIV non-adherence:

> Some of them feel they are healthy and shouldn't take any medication even though they have HIV. They feel they are stronger and begin to play pranks with their medication. We have a number of them and during this time adherence becomes a problem. They feel they are strong and can run and can do anything and probably do not need their medication. Some even doubt their status at that point seeing that they are very healthy.

Another HCW indicated that: "They cannot explain why they are healthy and taking drugs. They play and forget they are supposed to take their drugs. It requires constant counseling and follow-up visitation."

Subtheme 12.2: Unsupervised ALPHIV medication intake by caregivers

One of the HCWs indicated "The caregivers feel the adolescents are old enough to take care of themselves. They ask the adolescents to go take their drugs (unsupervised), but these adolescents do not." Another HCW corroborated that "the parents do not intensely supervise the administration of their ARV again. They assume the children are grown ups and should take their ARVs but that doesn't happen".

Subtheme 12.3: Poor-adherence by maternal and paternal orphans

A HCW indicated that adherence to medication is poor for maternal and paternal orphans who are ALPHIV:

> For another group especially for those who have lost one parent particularly their mother, their adherence is almost certainly poor. If their father is alive, the adherence is not good. Some have relatives but the intensity of supervision and care is not as good as it would have been with

> their mother. So, for those whose mothers are dead, the adherence is poor and so we must do extra counseling for the child and anyone who is their caregiver.

Subtheme 12.4: The difficulty of adherence in a boarding school set-up

Participant HCW3 indicated that: “Adherence is difficult in a boarding set-up. There are issues of stigma.”. He also indicated how the challenge is being addressed: “We try to make them disclose the status of the child to somebody in the school who can act as a caregiver while the child is within the school. This person will have to do the supervision.”

He informed that the timing of the school’s activities may be at variance with that of the adolescent’s time for taking her drug:

> Another factor is timing; the activities in a boarding school set-up is different from what they have at home. For an adolescent who has been taking the medication for 10 years at 7 am at home. At 7 am in the boarding school, this child will be at the assembly ground.

Theme 13: Addressing the Challenges of Nonadherence to ART

The HCWs unveiled the different strategies employed by the health facility to address non-adherence among ALPHIV from their day-to-day experience at the health facility and at the homes of these adolescent girls. The Subthemes below provide the necessary information that broadly describes the theme.

Subtheme 13.1: Adherence class for non-adhering ALPHIV.

A HCW indicated another strategy employed by the health facility to address non-adherence among ALPHIV: "Those who are not doing well with their medication are always sent to adherence class where they are taught on what to do. If they improve, they will leave the adherence class."

Another HCW indicated that: "Those who are fully aware of their status, we send them to adherence classes and get to access services themselves in the facility."

Subtheme 13.2: Viral Load Assessment to check for AGPHIV non-adherence

Two of the three HCWs indicated that the viral load assessment conducted for all ALPHIV helps to determine if they have been adhering to their medication: "The blood sample test result will also show if they are taking their medication regularly."

Subtheme 13.3: Direct Observation Therapy as a strategy to address non-adherence

HCW1 described the process of Direct Observation Therapy (DOT) to address non-adherence:

> yes, we had a case like that; data showed she was okay but her viral load was high. I was assigned the case and was placed on strict home care visitation. I was with this child for three months and was there when the child would take her drug before going to school (that is DOT; direct observation therapy). The mother caused the problem; the child was used to taking her drugs at 7 am but the mother was not consistent as she was giving her the drug at 6:30 am, 6:20am or 6:10 am. As a result, her viral load increased and so I was assigned the case. Once a child is on DOT, the next viral load will tell if there is an increase or decrease or total failure.

Subtheme 13.4: Pill counting as strategy to check for non-adherence

Another strategy for identifying non-adherence among these adolescents is pill counting as described by an HCW:

> For every appointment to pick up their drugs, we count their pills; they are not supposed to come to the facility with any drug left. If they have pills left, it means they are not taking their drugs. We have everything documented in the software in the facility; we know the quantity of drugs given to each adolescent. So, pills counting is one of the major ways we assess their adherence.

Subtheme 13.5: Addressing opportunistic Infections among AGPHIV

One of the HCWs indicated that, the facility with support from other partners, address opportunistic infections and other ailments respectively among adolescents living with HIV:

> there are drugs given for these opportunistic infections as prophylaxis like Septrin to the facility and are dispensed free of charge to these adolescents. We also have Fluconazole which is also dispensed free of charge in addition to the ARV. Also, the health facility with other partners I mentioned (earlier) have also provided other small drugs that we give to these adolescents when they visit the facility with other complains but it’s not comprehensive.

Subtheme 13.6: Caregivers escort support to ALPHIV

One of the HCWs informed that caregivers are expected to escort their adolescents during visits to the clinic to discuss issues with the healthcare workers:

> But if the caregivers will remain and come to the clinic with them to discuss issues together because there are factors, we cannot see that the caregivers know, eg, some will not take their drugs when there is no food and will not know even though we did not tell them that they should not take their drugs without food……. Sometimes, we get some of this information from the adolescents and so we need to talk to these caregivers to see how we can resolve some of these issues.

Data for Metatheme 4: Everyday Life

Theme 14: Girls' Everyday Life Experience

The peculiarities of living with perinatal HIV as adolescent girls were revealed when the three girls shared their daily life experiences in the study. These are discussed in the subtheme below.

Subtheme 14.1: Access to daily needs for adolescent girls with PHIV.

One of the girls informed how unperturbed she is: "I do not feel different because we are both human beings and its God that destined it like that." When asked what their daily needs were, one replied "food, personal toothbrush, cloths I will wear and my shoes. That's all". Another expressed her need to continue with school as this has been a major challenge for her and her mother, and she once had to drop out for lack of funds to pay the fees:

> One of my needs is my school. It was very difficult to put me in school this term. I had to work for people which is what we do … Sometimes, I do stay at home and lose a term just to go and work and get money for feeding and for school fees ... I do join my mum to look for any housework, cleaning work; we do take care of sick people.

This same girl (AG2) complained of a lack of food for the household and reported how she sometimes had to get some support from the church they attend: "Sometimes we go to the church to help our Pastor's wife to do somethings. She cooks and gives to us to eat and when we get home, we drink water and then sleep."

The third girl (AG3) informed me that, though her need includes her toothbrush, and 'inner wears' including her sanitary pads, her utmost need was to see her family live happy again: "I will need to be changing my toothbrush, my inner wears like in a month… (but) … "I want my family to be happy. I love it when we are all happy playing together and laughing together."

Subtheme 14.2: Peculiar challenges of AGPHIV

Each of these girls described a level of vulnerability, in themselves and for their households. One girl described how she and her mother cannot afford sanitary pads sometimes and how she improvises using used wrappers (clothes):

> We use old clothes, shoes but the pad aspect, we don't have money to buy it (sanitary pads). We instead use wrappers (cloths) sometimes when we cannot afford it. Any small money we have, we use it to buy a piece (of sanitary pads) and use it, exchanging it with the wrapper (cloth)".

One of the girls described a similar challenge when the father could not afford sanitary pads and the mother was unemployed:

> Because sometimes, he says he doesn’t have the money to buy it (sanitary pad) …. And my mother is not working. I do tell her so she can explain it to my dad … If he has the money, he will give her to buy it for me.

During the interview, one of the girls narrated how a fellow adolescent girl living with perinatal HIV attempted to take her live over her condition:

> One of the girls confessed that she missed taking her drugs for some time, drank kerosene and wanted to kill herself… it was (kerosene) …. They had to rush her to this hospital. They treated her and since then, she has been okay. She now takes her drugs and does not care what people say. She is very healthy and so no one will know that she is an HIV patient when she stays in the midst of people. She advised us that we should not let anyone intimidate us because of our status. We should continue life.

Subtheme 14.3: A parent’s highhandedness towards his AGPHIV

During the interview, AG3 complained (crying) of her father's highhandedness and not allowing her to play with her friends: "my dad doesn’t allow me to come out and talk with my friends? (crying).” She informed that her father beat her up when he learnt she has a boyfriend: “When my dad noticed it, he beat me up (in tears) and took the boy to the police station”.

Subtheme 14.4: Household Economic challenges faced by the girls

A girl indicated that her father's job is to rent out his car daily to raise funds, while the mother is a tailor. Another girl indicated that her mother would need a job and a shop for petty trade for the maintenance of the family:

> One of the assistance, is for her to work and the salary be sufficient for the management of our home; Also, if she can have a shop so that when we are back from school while she's at work, we can open the shop and sell somethings to make money.

She also indicated that: "While staying with the people we're living with, we fry "akara" (beans cake) to sell." The third girl (AG3) informed on the type of assistance she wants for her parents: "For my dad, the car he is currently driving is not his only and he pays daily to the owner. He is praying to God to buy his own because he only knows how to drive."

Subtheme 14.5: Relational life of AGPHIV

When asked about their relationship with boys, only one of the girls indicated that she has a boyfriend to whom she disclosed her HIV status to: "yes, I did (tell him about my status)". She also disclosed that her boyfriend was concerned about her ability to have a child which she said yes: he asked me that with me having HIV, if we get married, would we be able to have a child? I said yes. He then said, if that is the case, there is no problem with our friendship." She described what she told her boyfriend about having sex and him being tested for HIV: "About that, I told him I can't have sex with him until I get married and from there I will be tested (of HIV) and he will be tested. He then said "okay, there is no problem".

She also informed that her father is not happy about the relationship: “When my dad noticed it, he beat me up (respondent in tears) and took the boy to the police station”.

When asked about the reasons for not having a boyfriend, one of the girls (AGI) said “Because I have not yet finished secondary school, and I am not thinking of that (for) now.” While another of the girls said "because I don’t want to involve myself in dropping out of school. I want to achieve my dreams especially academically and to remove disgrace from my parents or to spoil the name of my family". The fear of contracting another disease in addition to the HIV she has, is another reason she also gave for not having a boyfriend: " I am living with HIV and (if I am) having sex with another person and not knowing what infection that person may have, might add extra load to carry (disastrous), increasing your own problem with the person". Giving her mother an extra burden to carry with their current health condition of living with a chronic disease, is the third reason she gave for not having a boyfriend: "You may get pregnant and make your mother who is paying your school fees, to suffer to feed you; you will add more stress to her (mother) stress."

Theme 15: Caregivers Challenges with Managing Child’s Condition

The daily challenges experienced by caregivers in managing the condition of their adolescent girls emerged as a major theme in the study. These are described through the Subthemes below.

Subtheme 15.1: Difficulties of caregivers in managing health condition of the girls

A caregiver described how she would have opted for a different job but now she must be near her daughter always and accompany her to the hospital for her appointments:

> Sometimes I choose the work I do because I don't want the job that will take my time….. she cannot come here (the facility) alone. I have to come with her because there is an express (highway)way; I can't risk it.

Another caregiver described how her daughter sometimes isolates herself from her (the mother) and gets worried over her health: "Sometimes she sits sad. I know some of her sadness is about her health if it's something she can do away with. I could read it from her." She also informed that her daughter also gets discriminated against as an orphan by some children in the community:

> As an orphan she gets discriminated against by other children who are not orphans especially when the children run to greet their father after returning from work; some children will say to her "go and look for your father. This is our own father.

Subtheme15.2: Caregivers' experience with girls' non-adherence

One of the caregivers narrated how her daughter was initially missing her drug: "She doesn't like taking drugs. Sometimes, I will call her and give her the drugs thinking she swallowed then only to realize that she did not. When I clean the house, I find the drugs in separate places."

Subtheme 15.3: Caregivers' advice to girls on relationship and sex

A caregiver described how she advised her daughter to focus on her education and not on relationship with the opposite sex: “She is not really into the opposite sex yet. Maybe because of the way I talk to her about it. I told her that everything is a phase; all she needs now is her education.”

Another caregiver informed how she educated her daughter about sex: “I discuss sex with her. She should not only stay away from HIV but from sex because of her spiritual growth………She’s a child of God”.

Subtheme 15.4: Addressing menstrual hygiene of the girls

One of the caregivers described how her adolescent daughter took care of her monthly menstrual flow:

> Yes, she did that herself, but she told me. I was at the shop when her period started though at that time her flow was little. So, she got herself a tissue and I commended her for that and gave her the money.

Another caregiver described how she provides sanitary pad for her adolescent daughter: “I provide it (sanitary pad) steady, but she discusses with me very much but there are times the menstrual flow does not come early.” and advised her not to discuss the issue of sanitary pad with anyone: “She wouldn’t discuss the issue of sanitary pad with anybody. She’s so free to discuss it with me.” The same caregiver (CG2) described how she improvise with her wrapper (cloth material) if she cannot afford a sanitary pad for her daughter: “There are alternatives sometimes when I don’t have (cannot afford it). She has asked me several times that she wants to use a cloth material I am not using. So, I let her use it.”

Subtheme 15.5: Activities for daily living (ADL) of AGPHIV

When asked if their daughters know how to take care of themselves apart from being able to take their drug, a caregiver indicated that: “because, the responsibility of the home, caring for herself and others at home has been on her, she does not need any push from anyone for her to take care of herself.” She described the house chores the daughter undertakes daily: “Yes. She cooks, sweeps, washes her cloths and those of her younger ones; they do it collectively. But the cooking and sanitation, she does them herself.” Another caregiver (CG2) described how she and her adolescent girl work together to provide for the family:

> But she’s an understanding child. I will say she’s, my partner. As a child, she grew up to know what I do and to learn the things I do. And so, we do things together so as to have somethings to feed together. But when the food is not there, she doesn’t see it as being maltreated…… we help ourselves in taking the drugs. If we are going out together to do our casual job, and I forget to take the drugs, she will laugh and say that she has picked the drugs already.

The third caregiver (CG3) informed that: “since she’s a lady, I cannot leave her to over labor herself; because of her health, I do not allow her to do difficult house chores except the easy ones.”

Theme 16: Household Needs of Caregivers of AGPHIV

In this study household need emerged as a peculiar theme describing the household condition of caregivers living with ALPHIV and the supports they need. The subthemes below provide more information about the theme.

Subtheme 16.1: Caregivers' Household Economic needs

When asked about their household needs, one of the three caregivers indicated that:

> "We will need finance to boost my business so that when I am more stable, it will not be difficult to sponsor them (the children) in school ……. If I and my husband are supported, then the children are secured. We will be able to meet their needs.

Another caregiver informed that:

> I need support; I need something doing. I feel more better when I can work and earn money. At times the household cleaning job comes once in a month and the money is not enough to take care of the family for a month. I hate being idle. …..For my daughter, I will want her to go to school…. I want support for her education.

Caregiver (CG3) informed that:

> My husband is a very hardworking person. His plan was that he would save some money from the business and buy his own car. But because of the family burden he currently has, this has been challenging. Where our

> daughter goes to school is at "Madala" and he gives her transport fare every day.

Subtheme 16.2: Transport support need for clinic visits by the girls

A caregiver informed that she had missed her hospital appointments because of lack of transport fare: "I have missed my appointments several times because of no means of transportation… and that her daughter faced similar challenge: "She doesn't attend the support group all the time especially when there is no transport even though they will give her transport fare when she attends." She also indicated that "Sometimes when I look at the transport to attend the support group meetings and the need for food, I prefer to stay away and use the money for food." She sometimes gets some support from friends: At times, I borrow money to transport myself but would not have money to pay back."

The third caregiver informed that: "Throughout last year, I did not take my drugs and so I started having problems with my health. This is because, it was difficult to transport my daughter and I to the hospital." She also indicated that: "It was difficult to feed at home and so I had to go back to the village."

Subtheme 16.3: External support provided to households of AGPHIV

When asked if they receive any external support to help them and their household, a caregiver indicated that she got some conditional cash transfer from a Community Based Organization (CBO):

> If you're taking care of your children and they are virally suppressed, it will encourage them to do more for you so that they remain suppressed; if

> you invest the money in your business and you're doing well, they will want to support more.

According to her, the health facility also provides some food support especially for her PHIV son: "they give food support every month"; "it is actually for the boy because he is much younger". As part of the support she gets, the caregiver (CG1) also indicated that her sister who is a teacher act as a treatment support person for her daughter when she goes to her (sister) place during the holidays:

> There are times that she goes on holiday too. Those times with my sister who knows her status. She (the sister) is like a treatment support person and so she has no issues with …. She (sister) keeps to time and so there has been no time or reason for her (the daughter) to miss her drugs.

A caregiver (CG2) indicated that: "at the earliest time when she was very sick, they were providing beverages but when she clocked 10 years, they stopped giving."

Data for Metatheme 5: Stigma

Theme 17: Stigma and Discrimination Experience by AGPHIV

The fear of stigma is evident in the lives of the girls because of their refusal to disclose their HIV status to some family members, school mates and persons in the community. Worthy of note is the fact that only one of the three girls indicated that she has personally experienced stigma and discrimination from her family. However, self-stigma was evident in all participants day to day lives.

Subtheme 17.1: Experience of stigma and discrimination by AGPHIV

Two of the girls indicated that they had not experienced stigma because of HIV in schools, within their families and from community members. However, one of the girls described how she and her mother experienced stigma from some extended family members: “she told her family; her siblings and her mum, that she has the disease. When they knew, they were scared not to contact the disease. They stopped using things with us. They are not free staying with us.”

Subtheme 17.2: Self-stigma experience of AGPHIV

One of the girls described her and her mother’s self-stigma experience: "She asked me not to tell people around me about it……sometimes she’s scared that whenever I play with other kids, they will contract the sickness, so she did not want anyone to know about it.” Another girl described how her father and mother told her to keep her status secret: “This is because, when I started taking the drugs, my dad told me not to tell anybody from the family… they asked me not to tell anybody outside."

Subtheme 17.3: Community perception of PLHIV by the girls

One of the girls described what community members say about people living with HIV: “Some of them say “God forbid them to stay with those kinds of people and then contact HIV and suffer” while another girl said: “……They usually discriminate against those who have HIV …they say something like, “this person is with HIV and I will not like to be close to the person.” They gossip saying all kinds of things about the person.”

Theme 18: Stigma and Discrimination Experience of Caregivers

In the study, the fear of their daughters and themselves being stigmatized in their daily lives was evident in the data collected from the three caregivers. The theme is discussed through the subthemes provided below.

Subtheme 18.1: Experience of stigma from family members.

One of the caregivers narrated how she and her daughter were stigmatized by members of their family when she summoned the courage to disclose the HIV status of herself and her daughter following the advice from the health facility: “After bringing my mother (to the health facility), she returned home (the village) and started picking all my siblings’ children and my siblings who were staying with me one after the other. I obliged her.”

Subtheme 18.2: The challenge of self-stigma

One of the caregivers described how she advised her daughter not to disclose her HIV status to anyone and that it was a personal thing:

> I wouldn’t want to share. It’s a personal thing. There is no point and I use to tell her”….. you don’t need to tell somebody about it one, you are doing well as long as you are taking your medication. And if somebody ask you why you are taking your drugs if somebody sees you. You tell them it’s your multivitamin you’re taking just to help yourself.

Another caregiver (CG2) informed that prior to her status disclosure, she suffered self-stigma for many years with her daughter:

> I faced issues with self-stigma for some many years with my daughter and would not allow her………. I used to stay in-doors and cry that we will soon die because I lost her junior brother.” She further narrated: “Since it was break or closing time, I will quickly run to my daughter and bring her close to myself not wanting her to play with other children and get them infected.

Another caregiver (CG3) indicated that the HIV status of her daughter has not been disclosed to persons in the community and the school where her daughter attends: “they don’t know”. She indicated that her husband does not allow their daughter to relate with other persons: “yes, because of her health, sometimes her father does not allow her to go anywhere for people to know she has a health problem, unless I go with her.”

Subtheme 18.3: Community perception of PLHIV by the caregivers

A caregiver narrated her initial experience with a co-worker about people living with HIV:

> She said, “if she sees HIV people she will run (away)”. But now that she is more enlightened, she talks one-on-one with them, she hugs them, she relates better. Judging from her own words, I will say that HIV in the community is still something that people stigmatize.

Another caregiver informed that stigma in the community has reduced: “yes. but I don’t think it’s much like before. With my mother’s experience coming here (health facility), she got to know that there is a family member who is HIV positive.”

Theme 19: Addressing Stigma Against ALHIV in the Health Facility

The three HCWs shared their experience on the type of relationship they have with ALPHIV, and the different strategies employed by the health facility to ensure no child or adolescent living with HIV is stigmatized or discriminated against.

A HCW indicated that “Adolescents are special to us, so we have to treat them well.” while another said “We have to show them love to see that they continue their treatment. There’s a way to treat them that will discourage them from coming again to the facility.” To ensure no ALHIV is stigmatized in the facility, a HCW informed that

> We especially train the staff in the clinic compared with the staff at the HIV center because we have capacity to relate with persons living with HIV. You may be surprised to know that a nurse (in the clinic) may not know much about these things, so we train them, so they do not stigmatize these children.

Another HCW informed about the health facility policy against stigma and discrimination and all staff are aware of this: “the hospital has a policy against stigma and discrimination. This is well understood by the staff and we have them pasted in the offices to guide how we relate with these people.”

To ensure the health care workers at the facility are up to date with guidelines, policies and new innovations/developments in the HIV intervention space, the health facility provides capacity building activities: “we do have trainings on such things for all the staff from time to time especially when there are new developments. We always have new staff and so we train and re-train from time to time.”

Data for Metatheme 6: Support

Theme 20: Support System for AGPHIV

The support system as acknowledged by these adolescent girls includes their family members (nuclear and extended families), the support group at the health facility and friends. The subthemes below discuss the themes broadly.

Subthemes 20.1: Varying support system for AGPIV

During the interview, one of the girls indicated that the adolescent support group meeting has been a platform to encourage adherence among Adolescents living with HIV like herself: “In the OTZ club, we have been separated into different groups. In the group each person calls their members to remind them when they are to use their drugs, come to the facility, to pick up their drugs”. Another girl said: I have one of the adolescents in the support group who calls to ask me if I am taking my drugs and when the next support group meeting will be." She also described how a HCW advised her about the support:

> Auntie at the health facility was the one who told me to come for the support group. She also said transport fare will be provided after the support group meetings. That I will learn a lot….the support group has really been a helping hand to me…yes, they give us food and money for transport.

She further indicated that her mother has been supporting her to take her drug: “I thank God I have a mother who is taking care of me, who tells me how to take the drugs properly and at the right time. So, I have no challenge.” The third girl described the financial support she got from her HIV positive auntie: "like the time I said my dad was having financial challenges, she (auntie) used to give me money so I can come collect my drugs. She is also taking the drugs too."

Subtheme 20.2: Support group as a good resource center for AGPHIV

One of the girls indicated that the support group provides some learning resources on HIV prevention and treatment: "They give us videos to watch (on HIV prevention and treatment)"; "I watched videos of other persons who are HIV positive (at the support group meetings)." Another girl informed that they were taught treatment literacy and described what it is all about:

> Yes, treatment literacy……that we should be taking care of ourselves, we should know the time and when to take our drugs, our appointment days and that we should be eating enough food, and we should be taking care of ourselves.

Theme 21: Adolescent Support Group at Health Facility

In this study, the three HCWs informed on the decision of the health facility to provide a peer support group for adolescents living with HIV as a platform for them to seek for and remain engaged in care. The subthemes below provide broad understanding of the theme from the experience of the three participants.

Subtheme 21.1: Adolescent support group meetings at the health facility.

One of the caregivers indicated what benefit the daughter enjoys from the adolescent support group meeting: in the facility, they talk to them about their health, and they enlighten them more on how to take care of their health." Another caregiver indicated that: "since she started the support group meeting, she has achieved boldness, communication and friendship.” The third caregiver indicated that: “They give her transport fare when she attends the meeting.”

Subtheme 21.2: Support group composition and “atmosphere”

One of the HCW described the composition of the adolescent support group: “In the adolescent support group, they have a chairman/team leader that gives them health talk on how to live their lives; how to behave well and how to take their drugs. They have a secretary. Their support group meeting comes every first Saturday of the month…….” Also, the HCW indicated that: the facility provides refreshments and transport fare for each of the adolescents once in a month.”

Another HCW also informed that these adolescents manage the support groups themselves:

> These adolescents research a lot about things happening in other countries; in the last meeting they came with a video on adherence that was shot in the US. They played the video and advised themselves. If they need any assistance, they talk with the HCWs.

A HCW further informed that:

> They interact freely with themselves, and it was through this forum that many of them got to know their HIV status. It was when HIV was being discussed that many of them started asking questions and went home to ask their parents why they’ve been attending the clinic and from there, disclosure happens.

Subtheme 21.3: Advantages of ALPHIV attending the Support Group meeting

A HCW informed that “Prior to this (support group), virtually all the adolescents were having high viral loads.”. However, “The number one achievement is that the number of adolescents with high viral load have reduced… within the period we launched this program, our suppression rate has improved dramatically combined with other interventions.”

Another HCW further informed that the ALPHIV have the privilege of learning from their life experience (since some of the staff are HIV positive): “We as staff also attend the meetings sometimes and share our own life experience with them. So, they see it in us; if you’re not doing well, you cannot talk to them (about adherence).”

HCW3 also indicated that: “We invite motivational speakers and teach them on skills acquisition; how to make soaps, shoes etc. We advise them on what they can do for themselves and ask them to demonstrate.”

Subtheme 21.4: Structured OTZ Adolescent Support Group

One of the HCWs informed on the sole reason the OTZ (zero missed appointment, zero missed drug, zero missed and zero viral load) was introduced into the adolescent support group last year: “to improve adherence among adolescents including adolescent girls and achieve viral suppression” He also indicated that:

> Part of the design of the program is to have an adolescent who is like themselves who becomes a champion so they can talk to other adolescents; they have one champion for girls and the other for boys. They reach out to other adolescents, interact with them and find out their difficulties so that they can achieve good viral suppression.

The HCW also described the success of the OTZ club: “With OTZ support group, the adolescents within the age range of 14 to 20 years have had improvement adherence and viral load suppression unlike before.”

Theme 22: Support System at the Health Facility for AGPHIV

In the study, the participants informed on the different support services provided by the health facility for adolescents living with HIV. This theme therefore summaries these services and are broodingly descried by the Subthemes below.

Subtheme 22.1: Support for Indigent ALHIV

One of the HCWs indicated that the health facility funds treatment and care for indigent ALHIV:

> The indigent group among these adolescents, and the hospital being a faith-based hospital whose mission is to serve the sick and less privilege, have a way of funding their treatment so that they don’t go away without any form of care.

However,

> It has to be proven that the client is an indigent before we can call on the health facility to assist otherwise the adolescent girl will either pay for the treatment or depend on the caregiver to pay for the treatment.

Subtheme 22.2: Food support provided by the health facility to AGPHIV

One of the HCWs indicated that: “Once a child’s arm circumference is going down, and the BMI is low, they place the adolescent on food support to boost the BMI.” The HCW further indicated that:

> This is provided monthly and can last for a long as possible. Some have been on this for as long as 5 to 8 years and are still on it. Sometimes both the adolescents and caregivers are on the same food support; while one is for the adolescent, the other is for the caregiver. We've been doing this even before the covid pandemic.

Subtheme 22.3: External Support to health facility

One of the HCWs described the external support the facility receives to support its services:

> We have a lot of partners working with us which provides support technically, logistics and materials, drugs supply and laboratory commodities. We also have partners which also provide support like food. The health facility sister organization themselves with their project office and mother house which also provide support reaching everybody including the adolescents, children and adults….Without the support of those people, we can't cope especially when it comes to drug supply because these drugs are expensive, and we cannot afford to buy them indefinitely and these adolescents cannot afford it either. So, we are dependent on that system to maintain treatment for them.

Data for Metatheme 7: Health Services

Theme 23: The Girls Experience With Healthcare Services

The girls expressed their experiences with the health facility where they access services daily as adolescent girls living with perinatal HIV. These experiences are discussed in the Subthemes below.

Subtheme 23.1: First time experience at health facility

In the study, the girls expressed their first-time experience when they visited the hospital and placed on ART. While one of the girls could not remember her experience when she first visited the health facility and placed on ARV, another girl expressed how unpleasant she felt: "When I first came to the hospital, they said this child will not survive." However, "I kept telling my mum I will live." She was further encouraged: "When I saw those kids with HIV, I did not feel bad because I was not the only one with HIV and felt that one day there will be a cure and I will be free from HIV". The third participant expressed how she was well received and treated by the healthcare workers at the hospital: "they treated me well……they welcomed me nicely and attended to me well."

Subtheme 23.2: Longer term experience at facility

All three girls agreed that treatment at the facility was okay and helped them to cope with their condition. One of the girls indicated that: "They give us the appropriate drugs to reduce the HIV. They take our blood to see if we are below twenty (20)." Another girl expressed: "It (the treatment) was helpful", and commends the facility for changing from a twice-a-day dosage to once-a-day dosage: "When the dosage was twice a day, sometimes when we go out, we take the drugs with us and there you have to feed yourself, and there was no much food…. yes, it is better (taking the drug once a day)." She added that she appreciated the client-friendly behavior she received at the clinic:

> I just like hospital. I like the way they treat people; the way they advise. We are used to them. We are used to all the doctors. When we need help,

> they help us. We will not be free the way we are free here if we move to another hospital … We want to continue coming. I told them I don't want to leave the hospital because I enjoy it here. I like everybody here (smiling) and I'm used to them.

The third girl indicated how the doctors counseled her: "Some of the doctors said that I was taking the drugs well but due to thinking that made me fall sick. While taking the drugs, you must be happy taking it otherwise the drugs won't work well."

Subtheme 23.3: Frequency and reasons for visits

A girl indicated that she visits the hospital: "once a month" while another said: "Anytime they want to take blood samples, see the doctor or whenever we have our support group meeting". Another girl said: "Whenever we have appointment; we come for blood samples when it's time for blood samples. We come for pharmacy when it's time for pharmacy. We come for doctor when it's time for doctor (Clinician), and the doctor advise us." The third girl included attending the support group meeting during her visit: "I come for drugs, to the pharmacy, blood sample and to see the doctor, and then the adolescent support group meeting every second week of the month."

Theme 24: Caregivers Experience With Health Services

In the study the views of the individual caregivers on the services provided by the health facility staff to their adolescent girls emerged as a necessary theme. A caregiver expressed her appreciation for the services provided by the healthcare workers at the facility especially the treatment arm: "Yes, the treatment at the facility has been very helpful because they check on virtually everything; she (daughter) saw the doctor yesterday who told her that her CD4, viral load is okay. He commended her." She also indicated that:

> So far so good, the health facility has been helpful because you don't want to default, and you don't want to be penalized; once you are not adhering 100%, you will be sent to the (adherence) counselor, and nobody wants that. She (counsellor) has been so helpful……Maybe because I've been long here, they've been very good. They don't make you feel inferior, they don't make you feel you are at a disadvantage. They've been nice.

Another caregiver expressed her gratitude: "Yes. Very helpful. In this place she (daughter) has found friendship, she can talk and some of the timidity has drastically reduced." The third caregiver also indicated that:

> Their services are good, and they are trying very hard because it's not easy… Even if there were no drugs, they will at least give me drugs that will last one month and ask me to come when the drugs are exhausted.

Theme 25: Caregivers' Account of Support Provided by Health Facility

One of the caregivers described the empowerment program provided by the health facility to adolescents living with HIV;

> For the adolescents, they've been doing excellently. There are times that we heard that ……..the facility helped the children through school, to pay for their exams, empowered some of those children through vocational skills training (sewing, hair dressing etc). They gave out some sewing machines to those trained.

Theme 26: HIV/AIDS Service Delivery at the Health Facility

The type and quality of services provided by the health facility for ALHIV was discussed by the three HCWs in the study, hence, the emergence of the theme in the study. The subthemes below provide a broad understanding of this theme.

Subtheme 26.1: Free HIV services provided to ALHIV

All the three HCWs indicated that all services provided are, “absolutely free. Everything is free for them. No user fees: their drugs are provided free, their laboratory tests are provided free of charge; clinic visits free of charge. They don’t pay for anything, no consultation fees.” A HCW also indicated that:

> It is good that the user fees have been cancelled. There was a time these children had to pay for their drugs and so they were missing their appointments. With the little support they get from the facility, this has been another thing that has helped to increase their number at the facility.

Subtheme 26:2: Types of Services provided to ALHIV at health facility

Although two of the HCWs listed the services provided by the health facility to ALHIV, one of them summed up all the services:

> This hospital offers comprehensive ART services. That includes adherence counselling, treatment preparation classes, clinic consultation to see their clinicians, laboratory monitoring (their CD4 count, liver enzyme, biochemistry, and viral load routinely), Pharmacy dispensary and DOT clinic affiliated with the ART clinic in case they have cough or any of those symptoms which makes them a suspect for Tuberculosis. We also

> have support group which is like small meeting for young people where they meet to discuss their issues and address their concerns. We also have food integration for those who are malnourished or for some other social reasons, we feed them from our food bank.

Subtheme 26.3: Differentiated Model of Care; multi-month scripting

A HCW informed that adolescent girls living with perinatal and behavioral HIV are provided with the same model of care: “we have differentiated model of care that include perinatally or behaviorally infected HIV. We do not separate them.” The HCW also informed that the facility provides multi-month scripting (MMS), family drug pick up, group drug pick up and fast track pick up:

> We have people who are on three months drug appointments in terms of multi month scripting; stable patients who are far doing well on three months drug, family drug pick up when a family member which could be an adolescent, caregiver comes to pick up drug for other members of the family. We also have group drug pick up where an adolescent can pick up drugs for other adolescents by proxy. We don’t practice community ART. We also have Fast track where patients who are doing well can come into the clinic to pick up their drugs and leave; they don’t wait to get their prescription from the doctor. Their prescription has already been provided.

The HCW also provided the condition for HIV clients to be placed on fast track:

> Before we place any client on fast track, we must ascertain that this person has taken ARV for one year and there has not been any adverse drug

> reaction and that this person is stable after examining this person's clinical examination and laboratory evaluation.

Subtheme 26.4: Inter-facility Relationship with other the health facilities

A HCW indicated that the facility has a good relationship with other health facilities whereby children and adolescents living with HIV are referred for other services: "we refer to the facility that has (such services) for the children to go pick up their drugs."

Theme 27: Health Care Delivery at Health Facility

In the study, the HCWs described the specific healthcare delivery approach of the health facility as it concerns persons living with HIV to achieve optimum health outcomes. The subthemes below, provides a broad description of the theme.

Subtheme 27.1: Family centered model of care

A HCW indicated that the health facility implements a family centered model of care for children and adolescents living with HIV:

> Because of those families who are positive, and whose appointments are tied together; so that if father, mother and child are positive, they can visit the clinic, collect their drug and get their blood test done on the same day. The design is that they come as a family.

He further indicated that:

> We don't have specialized clinics for children, adolescents and adults. Everybody comes to the same hospital, to see the same clinician, the same

> face but the only thing is that as the child is growing, we adjust the services as appropriate.

To manage a family centered model of care, the healthcare workers at the facility are trained in this regard: “Everybody is trained in that regard. So, we are offering both pediatric services and services tailored to adolescents and services to adults.”

Subtheme 27.2: Transition of ALPHIV to Adult Care

A HCW indicated that adolescents and adults are provided care together in the same clinic: “we don’t have anyone of them transitioned to the adult group (care). We group them together.” Hence “In that transition, a few things will change but the HCW remains the same. The drug regimen will be adjusted from what they were used to either by dose or the regimen itself.” He also indicated that:

> Some of them have grown bigger and so they have to take close to an adult or adult dose. The regimen too may change; some regimen we considered for children may have to be changed to adult like the new drug that is on board-Dolutegravir containing regimen. We now have to introduce it to them at that age.

Aside from changing their dosage or regimen, the HCW also informed: “Then the other transition that follows is that we may now have to interact with them directly (one on one) instead of going through their caregivers especially those who are 15-16 years old.”

One of the HCWs described the uniqueness of the transition model of the health facility:

> They are familiar with us and we are familiar with them. We know their problems from childhood and make sure that in their adolescent life, we factor in those problems they had when they were much younger into their care. We do not transition them to other personnel who does not have a full knowledge of some of the problems they have. This is an advantage and medically the child is complete seeing the same personnel and we've not found a problem with it.

Theme 28: Challenges Faced by HCWs in Providing Services to AGPHIV

In the study, the HCWs shared the challenges they experienced in providing services to adolescents living with HIV in the health facility. The theme therefore provides an understanding of these challenges and are broadly discussed through the subthemes below.

Subtheme 28.1: Barriers to service delivery

A HCW informed that there are two types of barriers to service delivery experienced in the health facility namely the ones from the healthcare provider and those caused by the adolescents:

> For the health care providers end, we sometimes run out of reagents and commodities because of logistic reasons, delay in supply, out of stock in the market as national problem etc…. we had stock out largely due to supply from the central logistic system… it happened many times last year

To resolve the problem of drug stock-out, the HCW stated that "……… we had to adjust the regimen of these adolescents to give them what we have since what they were on, was not available. This was confusion for many of them (clients) who complained." The HCW also indicated that: "Stock-out is largely out of our control and largely dependent on the central logistic system despite our commitment to complete all necessary documentations and logistics on time."

For the second barrier, the HCW also indicated that:

> From the end of the adolescent girls, many of them are dependent on their caregivers and parents for support to come and access services here. Some of them leave far away from the facility and so they need transport money to visit the facility. If they don't have transport money, they can't access their services.

Subtheme 28.2: Financial challenges of Health Facility

One of the HCW described a major challenge faced by the facility in providing services to ALHIV:

> The facility does not have the financial capacity to provide certain things for the adolescents. For example, we wish we could support their education, support them in skills acquisition and empowerment for all of them but we cannot. We can only support them to the level our resources allow. Yet, some of them have been empowered in terms of skills acquisition, and some have been assisted in their education in one way or the other.

Subtheme 28.3: Missed appointments & lost to follow-up at health facility

One of the HCWs also informed that missed appointments and lost to follow-up are two challenges that impedes service delivery: “Because the adolescents are dependent on their parents and caregivers, and the caregivers are the ones who keep the hospital appointment card, if they do not remember the appointment dates, the adolescents will not come to the hospital.” Also, “some of these adolescents are living with their relatives (aunties, uncles etc) who are not so enthusiastic to assists them (even with transport fare). Thus, lost to follow-up, missed appointments will be high and adherence will be poor.” However, “For those that are grown and are financially stable, they don’t miss appointments.”

Another factor fueling missed appointment as intimated by one of the HCWs, is that some adolescents living with HIV provide the wrong addresses: “We have problems with missed appointments because some adolescents give fake addresses. They do not want anyone to know their identity”. However, “Some give you the right phone numbers but do not want you to call them. Some travel far.”. Some of the adolescents travelled out of the state: “During the lockdown, majority of them travelled and when we called them, they say they are yet to return because they do not have money.”

Subtheme 28.4: How the health facility addresses missed appointments and lost-to-follow-up

To address missed appointments, a HCW informed that: “every day after work we assess the people who missed appointments and call them the next day. This helps to track them.” After this,

> If the person gives another excuse after the second call, you have to repeat the call after two months and conduct a follow-up visitation. The person is declared lost-to-follow-up after 90 days and then the file is closed. However, as we carryout follow-up visitation, we should be able to get the person back.

Subtheme 28.5: Lack of Reproductive Health Services for AGPHIV

One of the HCWs informed that:

> Being a faith-based, we do not promote the use of barrier contraceptives, condoms and things like that and some of these adolescents have been asking these questions and this becomes difficult for us….by the time they start getting to the age of 17-18 years, some of them starts thinking about relationships. They start asking questions around sex and sexual practices.

However, "for some; for those who need to be referred (for reproductive health services), we have some government-based hospitals around us, and tell them to access those services there."

Theme 29: Recommendations for Service Delivery

Subtheme 29.1: Recommendation for improved service delivery by the girls

To improve service delivery at the health facility, all the three girls provided their individual recommendations. One of the girls advised that testing for viral load, adherence counseling and support group meetings should continue. She however advised that: "They can be calling the adolescents in boarding schools who do not attend the support group meetings to remind them to take their drugs". Another girl also advised that the health facility should intensify follow-up activities with other adolescents who are not adhering to their drugs and advise them properly: “The problem is that there are other adolescents who do not take their drugs. They have to advise them and follow them up to ensure they take their drugs all the time.”

Another concern for this adolescent girl (AG2) is the payment for viral load assessment by adults (including caregivers and parents who are positive): “I want them to remove paying for the blood sample so that people can be free to come. Some persons will not even come for pharmacy.”

Subtheme 29.2: Recommendations for improved service delivery by caregivers

A caregiver advised the health facility to conduct some needs assessment for all adolescent living with HIV:

> They should have a time to discuss with the children, the adolescents so as to know the areas they need help. Not only for those who approach them for help but also those who do not know how to approach them for help; they should throw it open to all the adolescents.

Another caregiver complained of the N500 that is being collected by the health facility and the N5,000 collected from adults living with HIV for viral load assessment: “The N500 is not for viral load but it is only viral load we pay for. The viral load is N5000.”

One of the caregivers advised that the health facility should “continue to provide the drug (for free).” She however complained about the N500 being charged by the facility from adults living with HIV: “It was not like that before now. But now they tell us to pay N500 when we visit the hospital." She advised that the facility should continue to provide home-based care to their clients: "If they can be going to homes to treat their patients, it will be great." Also, "They should continue to provide other drugs when we have headaches or fever aside from the HIV drug."

She complained that the health facility has stopped advising them on what to do when they have side effects from the drugs provided:

> Formerly, they use to advise us that if we are not feeling well because of the drugs, they gave us, we should not take any other drug but come to the hospital so they can treat us or change the drug. However, they have stopped doing that.

Subtheme 29.3: Recommendations for improved service delivery by healthcare workers

When asked on how to improve service delivery for adolescent girls living with perinatal HIV, the three HCWs provided varying recommendations.

One of the HCWs recommended that the facility should continue to provide counselling for the adolescents and that the drugs needed should be made available in the facility: "Because, when we refer them to get drugs from other clinics, they won't go."

For those ALPHIV who are out of school because they cannot afford to pay school fees, one of the HCWs recommended that: "They need more of skills acquisition; some are out of school because they don't have funds to pay for school fees." One of the HCWs complained about not being able to conduct home visits for all the positive clients:

> Initially, we were visiting them (ALHIV) from time to time but because of the economic situation (in the country), some of the support we were

> getting no longer exist. As a result, we have to scale down our services and attend to only critical cases. Presently, not all the patients are visited.

The HCW therefore recommended: “we need to improve on HBC. We need assistance in the area of food supplements…. although we provide food supplements, not to all the adolescents.”

Another HCW also recommended the need for Insecticide treated nets (ITN):

> There are some of the things we usually get like mosquito nets for the children, but they are no more. This has helped in preventing malaria which has been a problem with these children and adolescents. We don’t even have Water Guard again which was used to prevent (remove) dirt in water; to make dirty water clean. These are needed.

One of the HCWs informed on the need to continue the adolescent support group meetings: “To keep the support group meeting going (because) they interact with themselves in the group and support themselves to address issues they individually face”. Also, the facility “should continue to shorten their stay in the hospital when they visit and provide enough drugs especially the ones in school (those who come with uniforms). We give especially attention to the adolescents when they visit the facility.”

Another HCW recommended that reproductive health services should be made available for these adolescents: “We wish services around those reproductive health are available and we can provide options for them but they are not there.”. The HCW also recommended the availability of weekend clinics for ALHIV in day schools:

> I also wish for these adolescents because of their school; I wish there's a weekend clinic. This is because, many of them are in school from Monday to Friday and so coming to the clinic is difficult. Some will have to miss school several times in a year (because of clinic appointments) …. the Saturday clinic will afford the adolescents to come to the clinic freely and access services and go home without the fear of missing school or exam.

Analysis of Metathemes

Metatheme 1: Knowledge of HIV Status of the Girls

Meta-theme 1 is defined by a cluster of two themes that discusses the experience of the girls about the meaning of HIV/AIDS, how it can be prevented and treated. It also covers how the girls got to know their HIV status, their reactions and advise from their caregivers about their status (see table 5).

On the knowledge of the girls about the meaning HIV/AIDS, none of them gave the real meaning as they attempted to pronounce the words accurately but could not. Concerning how HIV is transmitted, they indicated that it can be transmitted through sex, blood transfusion, through breastfeeding from an infected mother or when giving birth. Others includes the use of sharp objects or using toothbrushes with an infected person. For the girls, the prevention of HIV centered on avoiding the sharing of sharp objects with an infected person and keeping them safe from others, avoiding sex as an adolescent and avoiding the sharing of toothbrushes and screening of blood before transfusion. Taking care of oneself, eating well, and living in a clean environment were also identified as ways to prevent the spread of HIV.

All the girls indicated that their HIV status was disclosed to them as children by their parents; one of them disclosed that her father disclosed her status to her while the other two were disclosed to by their mothers. While two of the girls could not remember their age at the time of disclosure, one said she was seven years old at the time. Post-status disclosure reactions from the girls includes the feeling of being isolated because of frequently taking the drug as indicated by one of the girls while another felt bad and worried about how she got infected and why she had to be the one. One of them felt she was misinformed by her father who had indicated that she got infected through blood transfusion. She however, got to know that she was infected by her mother who later told her the truth.

Metatheme 2: Disclosure

Meta-theme 2 bundles three themes that discusses disclosure of HIV status by the girls (to their friends and family members), the experience of the caregivers on status disclosure to their daughters, and the disclosure experience of the healthcare workers working with the girls and their caregivers (see table 5).

For disclosure to their family members, one of the girls informed that her siblings got to know about her HIV status because they visit the clinic together (one of them is also positive). Another girl informed that her mother disclosed her status to her elder sister (mother's sister) while the third girl said her grandfather, aunties and uncles knew about her status as a result of the circumstance that led to her discovering her status.

Although their caregivers/parents advised them not to disclose their status to anyone, one of the girls informed that her mother informed her childhood friend about her status without her consent while another said she had to disclose to her friend because she (her friend) was worried about her frequent visits to the hospital. A girl said she has not disclosed to any of her friends as advised by her mother.

After her mother disclosed to her friend without her consent, one of the girls felt bad while the other girl who disclosed to her friend felt free because her friend still maintains the friendship with her and empathetic.

The caregivers narrate their unpleasant experiences prior to the knowledge of their daughters were frequenting the hospital too often because of one illness, one said she was tired of living because of the unknown illnesses which lasted for seven years. Another caregiver narrated how her daughter was transfused with blood because she was anemic.

One of the caregivers confirmed that her husband was the one who disclosed the HIV status of their daughter to her while she provided support later. Another confirmed that her daughter was eight or nine years when the mother disclosed her status to her daughter and that it was not difficult because they are “friends” while the other caregiver informed that her husband disclosed to their daughter, her HIV status.

On how they knew about their own HIV status, all the three caregivers narrated that discovering the HIV status of their children led them to be tested for the virus which came out positive. One of the caregivers narrated how she initially though her daughter got infected through blood transfusion.

The HCWs described the different types of disclosure which includes partial, full, and caregiver-assisted disclosure. A major factor to be considered for disclosure to

ALPHIV to take place is to ensure consent is obtained from the caregiver. Other factors include the cognitive development and personality of the adolescent; adolescents with good cognitive development tend to devise a means of knowing their status. One must be careful what is said to a child who is a talkative during the disclosure process. The overall factor is that must be trained to have the capacity to conduct disclosure.

A major challenge to caregivers allowing the HCWs to disclose the HIV status of their children to them, is the refusal to give consent. This is because of the fear of being stigmatized and the possibility that their child may disclose to others in the public. The caregivers feel their adolescents are not matured to handle the situation and are not certain of their reactions after the disclosure, hence, they hide their status from their adolescents. Post disclosure reactions from the experience of the HCWs include depression, trauma, secret confirmatory test since no symptoms are seen, being violent with the caregiver and many unanswered questions such as how and why they got infected with the virus. The HCWs also informed that they would prefer the caregivers to disclose to their children and only provide assistance when needed. They also indicated that the adolescents prefer their parents to disclose to them and not the HCWs. Because some caregivers refuse disclosing to their adolescents, the adolescents pick up the name of the drug and browse the internet.

Metatheme 3: Antiretroviral Therapy

Meta-theme 3 is defined by a cluster of eight themes that discusses the experience of the girls, their caregivers and the healthcare workers with reference to access to ART, concerns on long-term use of ARV, adherence to medication and treatment, common health challenges associated with ALPHIV, reasons for non-adherence among AGPHIV and addressing the challenges of non-adherence to ART (see table 5).

The adolescent girls had been on ARV but were not told until their HIV status was disclosed to them. They had been taking the drug without knowing the name of the drug but simply call it “HIV drug”. A girl narrated how the fear of dying made her continue with her medication while another narrated that initially, she was wondering about the illness in her that made them prescribe drug she was taking. The number of years of the girls have been on ARV ranges from 7 to 10 years. The main reasons the girls adhere to their medication are to have low viral load, the fear of dying from AIDS, to prevent mother to child transmission and to prevent loved ones from being infected. Dizziness was associated with one of the girls whenever she takes her drug without sufficient food. Also, another girl informed that the drug stimulates hunger and makes one sleep deep at night.

For the girls who are in day schools, missed drug was not a challenge however, missed drug/non-adherence was common in a boarding school as narrated by one of the girls. This was because she needed to avoid her friends who were too inquisitive about the drug she was frequently taking and the distance of the sickbay where she takes her drug to the class was too far. Another narrated how she stopped taking her drug because she felt healthy but was scolded by her doctor to continue taking her drug. Lack of transport fare to visit the clinic for drug pick-up was one of the reasons for missed drug and missed appointments as narrated by one of the girls. To ensure adherence to medication and treatment, the girls developed personal strategies with their mothers which includes the caregivers personally picking the drugs from the clinic especially during the exam period, taking their medication at the same time with their mother, setting an alarm as a reminder and using the Muslim evening call to prayer as a reminder.

The caregivers confirmed that they developed personal strategies with their adolescent daughters to ensure adherence to medication and treatment. This includes, setting alarms as reminders and taking their drugs the same time, calling on phone to remind them, and supporting their daughters to attend the support group meetings where videos on adherence was showed.

One of the caregivers confirmed that adherence was a challenge for her daughter who initially was in a boarding school and how she was advised by the Adherence Counselor at the facility to withdraw her child from the boarding school.

While discussing the antiretroviral treatment at the facility, the HCWs mentioned that the girls prefer the once-a-day regimen to the twice-a-day regimen because the twice-a-day regimen interferes with their school time, and a caregiver might not be available to supervise the adolescent. Also, the HCWs mentioned that these adolescents are mostly placed on second line regimen although few of them are still placed on first line regimen. However, pills fatigue is a challenge to adherence as two of the HCWs complained that some of these girls are tired of taking the drug.

Adverse drug reactions are not common among the girls who have been on ARV for many years. This is because, the best drug regimen was selected from childhood. However, where a side effect occurs, the regimen is adjusted by removing the offending drug and replacing it with a better one. The side effects may be due to excess doses of some drugs such as Nevirapine which causes hepatitis and efavirenz which causes nightmares. To address the adverse drug reaction, a follow-up/home visit is conducted by the HCWs once an adolescent is placed on ART.

The common health problems associated with adolescents living with PHIV includes malnutrition, body rashes (Papular pruritic eruption), diarrhea, malaria, typhoid, and toilet infection. Others include However, other health challenges may occur if there is immunological failure vaginal candidiasis and pulmonary Tuberculosis (rare).

To ensure adherence among the girls, the health facility adopted some strategies namely, the engagement of some home-based care officers as “Activists” or Role models who are themselves, PLHIV. The conduct home visits to encourage these adolescents to adhere to medication and treatment. A HCW indicated that adherence is better if both parents of the adolescents are HIV positive and for those who are fully aware of their HIV status. During the COVID-19 lockdown, adherence was ensured by referring these adolescents for drug-pick in near-by health facilities to their homes. However, some were not comfortable with the plan and so the alternative of taking the drugs to them was adopted.

The reasons for non-adherence from the context of the HCWs includes the adolescents not being able to understand why they take the drugs when they feel and look health, some are very playful and so forget to take their drug, and the caregivers refusing to supervise the administration of their adolescents ARV because they feel they are old enough. Adherence is poor for adolescents living with relatives because the intensity of supervision is poor, and adolescents who have lost one parent particularly the mother. In a boarding school setting, adherence is poor because of the fear of stigma.

To address non-adherence to medication and treatment, the health facility adopted the following strategies; referring adolescents with poor adherence and those who are fully aware of their status to the adherence class to be taught on how best to improve and how to access services respectively, viral load assessment which helps to determine the level of adherence, the Direct Observation Therapy (DOT) whereby a HCW works directly with a defaulting ALHIV to ensure adherence and pill counting whereby the pills of the adolescents are counted during clinic appointments to determine the level of adherence.

The HCWs informed that opportunistic infections and other ailments in case they occur because of non-adherence, are treated free of charge with prophylaxis such as Septrin and Fluconazole in addition to the ARV. Caregivers escorting the ALHIV during clinic appointments helps to address issues with adherence such as the ALHIV not taking their drugs when there is no food which is contrary to their doctor's advice.

Metatheme 4: Everyday Life

Meta-theme 4 is defined by a cluster of three themes depicting the everyday life experience of the girls, the caregivers' challenges with managing the health condition of the girls and the household needs of the caregivers with reference to the condition of their daughters (see table 5).

The daily needs of the girls include food (personal and household), personal toothbrush, cloths, inner wears, sanitary pad. One of the girls informed that her most important need is to attend school regularly and complained about lack of food in the house and how they get support for food from the church. Another girl informed that what she wants most, is for her family to live happy.

A major challenge among the girls is the inability of their caregivers to provide sanitary pads for them sometimes and so they had to improvise using old cloths. One of the girls informed on the suicidal tendencies of ALPHIV when she narrated how one of them in the support group attempted to commit suicide because of her health condition.

The girls revealed a very poor domestic economy when they disclosed the occupation of their individual mother and/or father. While one of the girls indicated that her father's job is to rent out his car to make money daily, another informed that her mother is jobless and that the family will need to engage in some petty trade to raise money. Another girl indicated that her father is a car driver who is praying to buy his own car one day.

When asked about their relationship with boys, only one of the girls indicated that she has a boyfriend to whom she disclosed her HIV status. Her boyfriend was concerned about her ability to have a child if they get married. She narrated how she told him they cannot have sex until they are married and that both will have to take the HIV test.; he agreed. She complained that her father is not happy about her relationship and complained about her father's highhandedness towards her for not allowing her play with friends how he beat her up when he learnt that she has a boyfriend. The other girls are not in any relationships because of the following reasons: to stay focused on their education and achieve their academic dreams, fear of dropping out of school, not to bring any disgrace to the family name if unwanted pregnancy comes, adding more stress or burden to the caregiver/mother and the fear of contracting another disease in addition to HIV.

The daily challenges experienced by caregivers in managing the condition of their adolescent girls includes restricting oneself to a job that is not so demanding so as to create time to stay near one of the girls always and to accompany her for their hospital appointments, sometimes, the girls do isolate themselves from others because of the worries about their health condition. A caregiver narrated how her daughter was discriminated against as a child because she is an orphan whose father died of AIDS.

In terms of relationship with the opposite sex and discussions on sex, a caregiver narrated how she advised her daughter to focus on her education so as not to get distracted. Another caregiver advised her daughter to not only stay away from HIV but from sex because of her spiritual growth as a child of God.

The caregivers confirmed what the girls said about their parents not being able to afford sanitary pads sometimes for them and so they had to improvise using tissues or old cloths from their mothers. A caregiver narrated how she advised her daughter not to discuss the issue of sanitary pad with anyone except her.

The caregivers narrated that their daughters know how to take care of themselves and others aside from taking their medication. They are engaged in house chores such as cooking, sweeping, and washing of cloths. A caregiver narrated that her daughter is her friend and that they have developed a mutual understanding and do casual work together to provide food in the house. A caregiver informed that she only allows her daughter to do the easy house chores and not the difficult ones because of her health condition.

The caregivers narrated their household needs to include finance to boost their business and that of their husbands to have funds for their children's education, and financial support for their husbands and themselves. The caregivers also corroborated the need for transport support as indicated by the girls. Lack of transport support for the girls and their mothers have contributed to missed appointments and missed drug and the inability of some of the girls to attend the support group meetings sometimes. A caregiver narrated how she prefers to spend her little money for food instead of giving it to their daughter to attend the support group meeting. She also indicated how she borrows money to support herself but cannot pay back. Another caregiver narrated how she missed taking her drug and her clinic appointments because of lack of transport fare and could not eat because there was no money and so had to travel back to the village. However, to support the household, a caregiver narrated how she got some conditional cash transfer from a Community Based Organization to assist her and her daughter. The health facility also provides some food monthly to the household of these girls and their caregivers.

Metatheme 5: Stigma

Meta-theme 5 clusters three themes which includes describing the experience of the girls as it relates to stigma and discrimination, the stigma and discrimination experience of the caregivers and the addressing stigma against ALHIV in the health facility (see table 5).

From the experience of the girls, the fear of stigma because of HIV (HIV-related stigma) was evident in their lives because of their refusal to disclose their HIV status to some family members, school mates and persons in the community as advised by their caregivers/parents. Of a particular interest, is the girl who described how her mother for fear of being stigmatized, who not want her to play with other children. However, one of the girls indicated that she and her mother experienced stigma and discrimination from family members. The girls believe community members still stigmatize against persons living with HIV and say things that shows they need to be educated about the virus.

From the context of the caregivers, one narrated how she and her daughter were stigmatized by members of their family when she summoned the courage to disclose the HIV status of herself and her daughter following the advice from the health facility. Another described how she self-stigmatized herself and her daughter when she advised the daughter not to disclose her HIV status to anyone and that it was a personal thing. She advised her daughter to tell her inquisitive friends she was taking her multivitamins if asked about her drug. A caregiver informed that prior to her status disclosure, she suffered self-stigma for many years with her daughter and how they used to stay indoors and cry, and how she would not allow her daughter to play with other children. A caregiver narrated that her daughter has not disclosed her status to anyone in the community and school. Describing the perception of the community about HIV and PLHIV, a caregiver indicated that stigma still exist in the community while another caregiver indicated that it has reduced.

To ensure the girls are not stigmatized or discriminated against, the HCWs show love and treat these girls with respect so they can continue to visit the facility and adhere to their treatment and medication. These HCWs are trained on current HIV/AIDS guidelines, policies, innovation/development in HIV intervention as well as to prevent stigma and discrimination against PLHIV. Also, the health facility has a policy on stigma and discrimination and all staff are expected to comply.

Metatheme 6: Support

Meta-theme 6 comprise of three themes which includes the describing the support system for the girls, the adolescent support group at the health facility and the support system at the health facility (see table 5).

For the girls, the support system includes the adolescent support group (OTZ) developed to support adherence, HCW at the facility, the caregivers, and members of the extended family. The support group provides learning resources including audio-visual materials and train the girls on treatment literacy.

From the experience of the caregivers, one informed that her daughter has achieved some level of boldness, improved in her communication skills, and has made some friends from the group. Another caregiver commended the facility for providing transport fares for adolescents who attend the support group meeting every month.

The HCWs described the support group as a well-formed group managed by the adolescents themselves with minimal supervision from the HCWs, and informed that the facility provides refreshments and transport fares monthly for those who attend the meetings. It is a platform that support social cohesion, status disclosure and adherence to medication and treatment and enjoys some motivational talks from some role models. The major achievement of the support group is the suppression rate has improved among adolescents. To further improve adherence and achieve viral suppression among these adolescents, OTZ (*zero missed appointment, zero missed drug, zero missed and zero viral* *load)* was introduced into the adolescent support group. The OTZ support group comprise of one champion for girls and the other for boys as leaders. With the introduction of the OTZ club, ALHIV age 14-20 years have had improvement adherence and viral load suppression unlike before.

The different support services provided by the health facility includes the provision of free services for indigent ALHIV, and monthly food support for malnourished children, ALHIV and their caregivers. To provide services to clients especially the provision of free drugs to clients, the health facility enjoys some external support from funders and other national and international partners.

Metatheme 7: Health Services

Meta-theme 7 is defined as a cluster of seven themes comprising of the HIV services provided by the facility, the experience of the girls with the health services, caregivers experience with the health services, the caregivers account of the support provided by the facility, the healthcare delivery at the facility, the challenges faced by the HCWs in providing services to AGPHIV and recommendations for service delivery (see table 5).

The girls expressed how pleasant the HCWs were when they visited the health facility and placed on ART for the first time. However, the experience of one of the girls was not pleasant because a HCW said she would not live because of how fragile she looked. She was determined to live and was encouraged when she saw other HIV positive children like her at the facility. The girls appreciate the services provided to them by the HCWs which includes viral load assessment, provision of free drugs, changing their twice-a-day dosage to once-a-day dosage which is better and the client-friendly behaviors of the HCWs which make the ALHIV free to relate with all the staff. All the girls indicated that she visits the clinic once a month for various HIV services such as drug pick-up, viral load assessment, meeting with the Clinicians and attending the support group meetings.

The caregivers appreciate the services provided to their adolescent girls by the facility and commented that the treatment has been helpful and that their viral load has been suppressed. They also commented on the friendly attitude of the HCWs which they say does not make them feel inferior or disadvantaged, and that drugs are provided to them even when there is shortage at the facility. A particular caregiver commented how her daughter has found friendship and she is no longer timid while another appreciated the education support program implemented by the facility which some ALHIV have benefitted. This includes paying for their school fees, and exam fees, providing vocational skills training and empowerment programs such as providing sewing machines, hair dressing equipment etc.

The health facility provides all services to the ALHIV free of charge as this has helped to increase the number of ALHIV accessing services at the facility. The facility provides comprehensive ART services including all the complements of HIV services including support group meetings for adolescents and adults. PHIV and BHIV adolescents are provided with the same differential model of care and benefits from multi-month scripting (MMS) for three months, family drug pickup, group drug pick-up and fast track pick up to encourage adherence. However, for fast track, the client must have been on ARV for a year without any adverse drug reaction and has been stable after some clinical and laboratory evaluation. The facility maintains a good relationship with other health facilities so that ALHIV access referral services not provided by them.

The health facility implements a family centered model of care for children and adolescents living with HIV and so there are no specialized clinics separately for children, adolescents and their parents who are HV positive. This means that, families with positive children, adolescents and parents have the same appointment days so they can visit the clinic, collect their drug, and get their blood test done on the same day. Thus, HCWs are trained on the family centered model.

The absence of a specialized clinic for children, adolescents, and adults, aligns with the model of not transitioning ALPHIV to adult clinic (care) but are provided services together with the adults and having the same HCWs provide services. At his point, the drug regimen, or doses for the ALPHIV will be adjusted to adult dose since their weight may have increased and direct interaction (communication) established with these ALPHIV instead of going through their caregivers especially for those from 15 years upward. The advantage of the transition model is that the adolescents are familiar with the same medical personnel from childhood to adult care and so problems from childhood are factored into care as they transition.

The challenges experienced by HCWs in providing services to ALHIV are categorized into two barriers namely the health care providers barrier and the barriers caused by the adolescents. The health care providers barrier includes reagents and commodities stockout due to delay in supply or stockout from the central logistic system.

To address these challenges, regimens were adjusted to give what was available to the adolescents. For the adolescents' end, barriers are caused by their dependence on their caregivers for transport fares (especially those who live far from the facility) and other supports. When these are not provided, they cannot access services at the health facility. The facility also faces some financial challenges and so some services such as educational support, support skills acquisition and empowerment are provided to a few of the adolescents.

Factors fueling missed appointments and loss to follow-up include the caregivers not remembering the appointment dates of their adolescents, the adolescents living with relatives who are not enthusiastic to assist them with their care even to transport fares for them to visit the clinic. However, the financially stable adolescents do not have these challenges. Other factors include some adolescents who do not want the HCWs to visit them at home and some who traveled far during the COVID-19 lockdown. To address these challenges, the HCWs engage in follow-up visitation and phone tracking.

A major challenge the study identified is the lack of reproductive health services for adolescent girls with PHIV because the facility is a faith based one. Hence adolescent girls who require this service especially those 17-18 years are referred to government own hospitals not far from the health facility.

To improve service delivery at the facility, all the participants provided their recommendations as follows.

The girls recommended that viral load assessment, adherence counseling and support group meetings for adolescents should continue. Others includes intensifying follow-up calls for adolescents in boarding schools and in other setting who are not adhering to their medication, and to abolish the viral load assessment fees for their caregivers/parents who are HIV positive.

The caregivers recommended that needs assessments should be conducted by the health facility to ascertain the exact needs of these girls to help them appropriately, the administrative fee of N500 and viral load assessment fees of N5,000 should be removed to allow more adults who are HIV positive to access services at the facility, and that home-based care provided by the facility should continue. Others includes the provision of drugs to address other ailments such as fever, headaches etc and providing counseling on what to do when they have drug side effects.

The HCWs recommendations includes to continue to provide counseling services to the adolescents, ensure all drugs these adolescents need are made available in the facility since they do not like to access these drugs from other facilities when referred, and to increase the number of out of school ALHIV who are accessing the skills acquisition program provided by the facility, and to increase the number of ALHIV being provided with home based services which was reduced due to some financial changes experienced by the facility. Other recommendations includes the need to continue with the adolescent support group meetings, to increase the number of ALHIV benefiting from the food support program of the health facility, to introduce the provision of insecticides treated net (ITN) to help prevent malaria which has been a problem with the children and adolescent accessing services at the facility, to continue to increase the turn-around time for these ALHIV when they visit the facility and the provision of water disinfectants to assist these ALHIV have and drink clean water. The provision of reproductive health services and weekend services for those ALHIV who cannot visit the clinic for their appointments during school hours Monday to Friday.

Summary

Chapter 4 outlines the purpose and research questions of the study as described in Chapter 1, the research setting, methods of data collection and analysis, then presents the results. The meta-themes, themes and subthemes arising from the data are outlined in Table 5.

Chapter 5: Discussion, Conclusions, and Recommendations

The purpose of the study was to explore the lived experience of adolescent girls living with PHIV in Nigeria in accessing services and adhering to medication, including the roles of families and health facilities. The study sought to understand the impact of long-term exposure to HIV and ART by adolescents with PHIV, and to understand the barriers and facilitators of such barriers that could hinder or have hindered adherence and access to ART (Galea et al., 2018). In this chapter, I provide the interpretation of the findings of the study, limitations, recommendations, implications, and conclusions.

Interpretation of Findings

I have provided the seven metathemes, 29 themes and 90 subthemes that emerged from the data analysis conducted across the three categories of research participants: the adolescent girls living with PHIV, the caregivers/parents of these adolescent girls, and the healthcare workers providing HIV services to the adolescent girls. The discussion in this chapter is provided as responses to the four research questions of the study.

RQ1: What is the lived experience of Nigerian girls living with PHIV regarding personal, family, and social challenges in access of health services and adherence to ART?

The peculiarity of the adolescent girls is that they were all infected with the HIV virus through their mothers and so their individual experience in living with the virus and managing their health is discussed here in response to the research question.

Metatheme 1: Knowledge of HIV Status of the Girls

The study shows that the girls have a fairly accurate knowledge of the meaning, prevention, and transmission of HIV, which they may have learnt from school or support group meetings. Although in their responses, some information provided were correct and some were incorrect, they lacked important information about HIV/AIDS and so they have low comprehensive HIV/AIDS knowledge. This aligns with the findings in literature that the comprehensive knowledge of HIV in Nigeria among adolescents is low (UNICEF, 2017) and stresses the need for adolescents to have the correct knowledge about HIV/AIDS prevention, treatment, and care. As adolescent girls who have lived and will continue to live with the virus for a very long time, it is important for them to have a comprehensive knowledge of the virus, including how it can be prevented, transmitted, and treated, to empower them to make informed decisions about their health and sexuality and to build confidence in relationships (Avert, 2020).

Findings from the study also revealed that the knowledge of their HIV status was disclosed to the girls by either of their parents at an early age between 7-10 years although they had been initiated on ART some years earlier. This resonates with the Nigeria National Guidelines for Pediatric HIV/AIDS Treatment and Care on the need for early HIV status disclosure for children which is 5-7 years old and should take into consideration the child’s cognitive ability as well as consent of parents/caregivers (Federal Ministry of Health, 2020).

The knowledge of their status was welcomed with mixed reactions. While one of the girls did not feel bad as a child, the others had bad feelings and worries about how and why they got infected with the virus. However, one of the girls felt she was misinformed by her father who earlier told her she was infected through a blood transfusion. She later learned this was not true. This is similar with other studies which indicates that some caregivers lie to their children when asked questions concerning their diagnosis (Okolo-Francis, 2021). Although the emerging theme shows different reactions to disclosure by the research participants, disclosure of HIV positive status to children and adolescents as documented in literature and is known to elicit negative and emotional reactions (Okolo-Francis et al., 2021) as shown in this study.

Metatheme 2: Disclosure

Perhaps to avoid revealing the HIV status of the caregivers to other persons for fear of being stigmatized, findings shows that their caregivers pleaded that the girls should not inform anyone about their (girls) HIV status (for the possible fear of being stigmatized). However, the disclosure of their HIV status to family members was either because a sibling was also HIV positive, or a parent decided to tell a relative they trust, or felt it was time for some family members to know about their status, or because a relative was available at the clinic when the discovery was first made. All these are summarized as the disclosure challenges of the adolescent girls and are supported by Folayan et al. (2015) who reported that the fear of stigma or discrimination among others, are the reasons for nondisclosure of HIV status. This was further corroborated by Mbadiba & Mokgatle (2016) who indicated that some perinatally infected adolescents keep their HIV status secret because it confers some level of control for them and gives them the power to decide who should or should not know about their status.

Despite the advice of their caregivers not to disclose their HIV status to anyone, a caregiver disclosed to the childhood friend of her daughter without her daughter's consent who was furious over this while another girl disclosed to her friend because the friend was bothered about her frequent visit to the hospital. She felt free after disclosing to her friend. In both cases, the friends were supportive and empathetic after knowing the HIV status of the girls. Thus, the study shows that the girls prefer selective disclosure whereby they decide on who to tell and who not to tell their HIV status and not their caregivers disclosing on their behalf (Wyks & Davids, 2019). According to literature, in some cases, disclosure of HIV status to friends by adolescents resulted in stigmatization and subsequent emotional trauma and secrecy, however, some who disclosed to their friends were supported (Mbadiba & Mokgatle, 2016) as reported in this study.

Metatheme 3: Antiretroviral Therapy

The long retention of these adolescent girls in ART care and ensuring good adherence is the pre-requisite for having good viral load suppression which invariably leads to them being clinically stable. Because they have been on ART for many years, the adolescent girls living with perinatal HIV have experienced various challenges and have developed appropriate individual adherence strategies to address the challenges experienced when taking their medication. This notwithstanding, the study shows that despite being on ART for seven to 10 years the girls simply called the drug "HIV drug" because they do not know the name of the drug prescribed for them.

Prior to their HIV status disclosure all the girls were initiated on ARV without knowing the nature of the illness in them. However, their concerns such as the fear of dying from AIDS, have low viral load, prevention of transmitting the virus to their future children and life partners were reasons these girls gave for adhering to their medication for such a long time. Findings also shows that these girls-built resilience on how to address their worries on their long-term use of the drug from the support they get from their mothers, the understanding they have about the importance of adherence and by attending the support group meetings at the facility. During the support group meetings, the girls are taught some coping skills and adherence strategies.

Challenges associated with taking their drugs include dizziness due to insufficient food intake, induced hunger, and deep sleep at night. However, challenges experienced by these adolescent girls when they miss their medication includes body weakness, dizziness, low viral load, headaches, and internal heat.

Among these girls, non-adherence (missed drug) was because some felt they were healthy and so they stopped taking their medication, lack of transport fare to visit the clinic for drug pick-up and the far distance between the sickbay and classroom for the girl who was in the boarding school.

To adhere to their medication and treatment, each of the adolescent girls developed personal strategies with their caregivers which includes drug pick-up by their mothers especially during school examination periods, taking the medication the same time with their mothers and setting alarms on their phones or wristwatches or using the Muslims call for prayers to remind them when to take her drugs. Thus, these girls have developed resilience and enjoyed some form of social support from their caregivers (mother-child bond with similar health chronic health condition) and health facility necessary to enhance and encourage ART adherence as evidenced in this study (Wyks & Davids, 2019).

Metatheme 4: Everyday life

The experience of living with a chronic disease especially for persons at the stage of adolescence which is characterized by changes, exploring new innovations and ideas and searching for identity, can be very limiting and challenging on the day-to-day lives of the girls. The daily lives of these persons revealed their daily needs, relational life with peers, and relationship with family as girls living with perinatal HIV.

All the girls indicated that their daily needs include having their toothbrushes, cloths, shoes, regularly attending school, inner wears, and sanitary pads. They also indicated that their parents are the ones who provide these needs when they can afford them. Hence, the girls want their caregivers/parents to be supported especially in the payment of school fees and household needs. Worthy of note is how one of the girls indicated that her coping mechanism includes believing that her illness is God's will for her. Obviously indicating a strain in the family dynamics due the presence of HIV, one of the girls indicated that she wants to see her family live happy and play together.

The study identified a major challenge that is peculiar to the girls, which is the inability of their caregivers to constantly provide sanitary pads monthly to them due to their poor domestic economy. Hence, they improvise with old cloths or tissue papers to help themselves, indicating very poor menstrual hygiene management among these girls and their mothers.

The possibility of these group of persons attempting suicide was highlighted in the study, thus revealing their level of vulnerability and the possibility of not having appropriate coping mechanisms to build resilience as they manage their chronic health condition.

The vulnerable state of their households as revealed by the girls, shows a very poor domestic economy. This is a major concern of the girls especially the ability of the caregivers/parents to regularly provide for their needs since they are also HIV positive and are engaged in menial jobs or are sometimes jobless. The girls are therefore soliciting for some form of economic support for their caregivers and their households

In terms of their relational life, most of the girls prefer to focus on their education and avoid having a relationship with the boys especially avoiding teenage pregnancy or contracting another disease aside from HIV. However, one of the girls indicated that she has a boyfriend who is aware of their HIV status and has agreed not to have sex with her until they are married. She indicated that she was beaten by her father when he got to know about the relationship and narrated how he asked the police to arrest the boyfriend. She is afraid of her father but relates well with her mother. She complained (crying) about her father's highhandedness in relating with her especially not allowing her to meet or relate with her friends in the community.

Metatheme 5: Stigma

The fear of being stigmatized or discriminated against because of HIV was evident in the study as caregivers of these adolescents had instructed them not to disclose their HIV status to anyone. This has characterized their lives and determined how they relate with extended family members, friends in school and people in the community.

These girls do experience stigma and discrimination from some relatives who get to know their HIV status. However, some are yet to experience any form of stigma and discrimination because they are yet to disclose their status in public as advised by their caregivers/parents. This indicates how concerned the girls are about how they are perceived in the social ecological ladder. A girl disclosed her actual experience of self-stigma on how at the early stage when they (herself and mother) knew about their status, her mother would not allow her to play with other children for fear of infecting them with the virus. In their quest to understand the experiences and effects of HIV-related stigma among youths with HIV/AIDS in Western Uganda, Kimera et al (2020) reported similar findings where youths living with HIV/AIDS (YLWHA) were constantly living in fear of revealing their HIV status for fear of being stigmatized.

Community perception of ALHIV reveals ignorance by some community members about HIV as these persons do stigmatize and discriminate against persons living with HIV. One of the girls complained that her father does not want her to relate with friends where they live and as a result, she is always at home with her younger ones. Although this is indicative of poor parenting and a poor caregiver-child dynamics which could negatively impact the child’s development outcomes (Lentoor, 2017), it also reveals a deep internalized stigma by the caregiver which produces negative outcomes (Kimera et al., 2020). For a more secured relationship between caregiver and child, the child considers the caregiver/parent as caring, responsive, and stable thus, providing him/her the security for exploring the environment, grow and develop (Lentoor, 2017).

Metatheme 6: Support System

Adolescent girls living with HIV need to be supported to help them meet their needs, address their challenges as well as assist them in managing their condition especially in adhering to their medication and having a positive view about life; being able to build resilience.

From the three girls, the adolescent support group at the health facility has been a source of encouragement as members often call themselves on the phone to remind one another of the time to take their drug and meeting days and time. The support group is regarded by the participants as a good resource platform for peer-to-peer learning on various relevant topics such as HIV prevention, adherence (treatment literacy) using audiovisual and other types of materials for learning. It also a platform for social connection among peers where resilience and other coping skills are built by these adolescents living with HIV. The health facility provides refreshments and transport fares once in a month as incentives for the participants who attend the support group meetings once in a month.

The family support described by the girls includes financial assistance from parents or extended family members who are aware of their HIV status to visit the clinic for their appointments. One of the girls described how her mother has been very supportive in assisting and encouraging her to take her drug at the right time. The healthcare workers at the facility have been very supportive encouraging them to join or attend the support group meetings at the health facility.

Metatheme 7: Healthcare Services

Because their peculiar health condition allows them to consistently visit the clinic for one reason or another in managing their health, the healthcare system plays a vital role in the health outcomes of adolescents living with HIV (Woollet et al., 2021). Hence the need for the continuous existence of adolescent friendly and efficient services cannot be over emphasized. The girls expressed varying experiences about how they were received when they first visited the health facility and placed on treatment. One of the girls had a negative experience because a HCW told her mother she would not live because of how fragile and sickly she looked when they first visited the clinic, the other girls shared pleasant experiences about how friendly and kind the HCWs were when they first visited the clinic and placed on ART. Generally, the girls agreed that their monthly visit to the facility for treatment such as viral load assessment, support group meeting, meeting with the clinicians and for drug pick-up or refill was helping them cope with their health condition. They expressed appreciation for their low viral load because of consistency in medication supply from the health facility, and the client friendly approach shown by staff of the clinic.

RQ2 What is the lived experience of family members of Nigerian girls living with perinatal HIV regarding access to health services and adherence to ART?

The Adolescent-caregiver relationship is critical for providing the necessary support for managing the health of adolescent girls living with PHIV, not just because of the mother-child bond but because they share a common chronic disease and one (caregiver) infected the other (adolescent girl) with the virus. Caregiving therefore becomes complicated as the caregiver manages her own health and that of the child from childhood to adolescence. Caregiving could be further complicated if a parent (possibly the mother) dies and the function of caregiving is provided by relatives (which could be uncles, aunties, or grandmothers), thus, changing the family structure. Because as a chronic disease, HIV negatively impacts the domestic economy of the household, caregiving is invariably affected by inadequate material and financial resources. Thus, there are studies indicating that the mother-child bond considered as a family within the context of SEM with appropriate interventions could provide the capacity for the caregiver to cope with her condition as well as help build the psychological resilience in their children/adolescents (Lentoor, 2018).

Metatheme 2: Disclosure

Prior to knowing the HIV status of their daughters, each of the caregivers described how they visited the hospital several times for years with their daughters because of one illness or the another until their daughters were diagnosed with HIV.

The caregivers described different scenarios about how the HIV status of their daughters were disclosed to them by themselves or their husbands with support from them (the mothers), and how guilty they felt being the ones who infected their daughters. Although the disclosure process was challenging, a caregiver described her daughter as her friend and how their relationship helped her disclose to her daughter without challenges. Although these adolescent girls were very young at the time of disclosure confirming the findings from the girls, the caregivers felt some form of guilt for allowing them to continue taking their medication without knowing the reasons or illness affecting them and that sooner, or later they will start asking questions. Similar findings about caregivers feeling guilty for infecting their children with HIV and having challenges with disclosing their HIV status has been reported in literature (Folayan et al., 2015; Galea et al., 2018).

Following the knowledge of the HIV status of their daughters, the caregivers described how they got to know their own HIV status after discovering the status of their daughters. Because her daughter was anemic at a time and had to be transfused with blood, a caregiver thought her daughter got infected via blood transfusion until she had to be tested of the virus and realized she infected her daughter. Findings from the study supports the findings in other literature that Nigeria is a major contributor to the number of new HIV infected children globally due to the country’s poor prevention of mother to child transmission interventions (Cohen, 2018; NACA, 2019; UNICEF, 2017).

Metatheme 3: Antiretroviral Therapy

Managing the health condition of their adolescent daughters means supporting them to adhere to their medication as prescribed by their doctors. To achieve this, the caregivers developed different strategies with their daughters to ensure adherence which includes threatening them with sickness and AIDS-related death, taking their medication together at the same time since they are both HIV positive (mother-child bond), encouraging their participation at the adolescent support group meetings where they are further encouraged to adhere to their medication and encouraging the use of an alarm device (mobile phone or wristwatch) as a reminder.

A caregiver described the challenges her daughter faced adhering to her medication when she was in the boarding school. She described how the friends of her daughter kept probing to know why she was always visiting the clinic and taking her medication daily. To avoid their disturbing probe, the daughter will deliberately skip taking her medication for somedays. The caregiver had to withdraw her daughter to a day school on the advice of the adherence counsellor. This finding resonates with other similar research describing the difficult situations adolescents living with HIV find themselves in adhering to their medication in boarding schools. In trying to understand the factors surrounding the ART adherence of ALHIV as well as their experience in Southwest Uganda, Kihumuro et al. (2021) discussed how some ALHIV in boarding schools conceal their HIV status to avoid unintended disclosure by hiding to take their pills or provide some false reasons for taking the pills.

Metatheme 4: Everyday Life

Caring and supporting adolescents living with perinatal HIV can be burdensome, time consuming and emotionally challenging because the caregivers are also managing their health condition and use the same clinic as their adolescent girls.

The daily challenges these caregivers face in managing the health condition of their daughters includes getting a job that is less demanding and nearer home to keep watch over their daughters and continue to provide the necessary care including escorting them to the clinic for their appointments, having to deal with depression when a child isolates herself from everyone because of her condition or when she is discriminated against as an orphan with PHIV or by family members, and reducing the house chores assigned to them to only those that are less burdensome.

All the caregivers who participated in the study are women thus agreeing with the fact that the primary role of caregiving for a child lies with the mother. These findings further emphasize the importance of the caregiver in assisting the girls with PHIV in managing their health and the impact HIV has on the role of the caregiver especially when they are also infected with the same virus (Lentoor, 2016).

A caregiver described how her daughter missed taking her drug by pretending to have swallowed them only to throw them away without her knowledge. McCarthy et al. (2018) reported that the long-term commitment to ART coupled with the associated fatigue of living with PHIV, may cause some ALPHIV to desire a break from taking the pills or displaying some pranks.

The relationship of their adolescent girls with the opposite sex has been a concern for all the caregivers. All the participants described how they counseled their adolescent girls about sex and to desist from having any intimate relationship with the opposite sex but rather concentrate on their education. However, a caregiver indicated that her daughter is a child of God and so her spiritual growth should be her focus and not having a boyfriend while another caregiver indicated that she is not happy that her daughter has a boyfriend despite her advice to her. The caregiver-child relationship as depicted in this study supports Lentoor (2016) findings that effective parenting is a necessary precursor to caregiver-child dynamics and facilitates optimal development outcomes in children providing the child with secured confidence to explore her environment, grow and develop. Doat et al (2019) reported that it is not common for parents to openly discuss sex with their children in sub-Sahara Africa, and so HIV infected caregivers do not discuss sex with their infected children for fear of being asked how they got infected with HIV. This is at variance with one of the findings in this study as two of the caregivers openly discussed sex with their infected adolescent girls and one of them introduced a "spiritual" dimension as the reason for her not to engage in sex.

Another major concern for the participants is the need for their adolescent girls to maintain proper menstrual hygiene management despite their health condition and household economic challenges. All the caregivers described how their adolescent girls know how to ask for sanitary pads when the need arises, however, when the participants cannot afford to buy them, they improvise using toilet tissues or used cloths. An essential part of a woman's life is hygiene during menstruation and so special healthcare is needed during this period. Caregivers of these adolescent girls should have the capacity to provide menstrual hygiene management and should enjoy some support from the health facility (Deshpande et al., 2018). Menstrual hygiene management is defined by the United Nations as "women and adolescent girls using a clean menstrual management material to absorb or collect blood that can be changed in privacy as often as necessary for the duration of the menstruation period, using soap and water for washing the body as required, and having access to facilities to dispose of used menstrual management materials." (Deshpande et al., 2018. Pg. 1440).

All the caregivers described their adolescent girls' activities for daily living (ADL) to include being able to take care of themselves, cook, wash their cloths, and sweep the house despite their health condition. A caregiver described her daughter as her partner and how they both engage in domestic jobs to raise money for the upkeep of the family.

Majority of the impact of living with adolescents with PHIV in the family falls on the caregivers or parents and affects the lives of every family member including the livelihood of the family. In the study, the caregivers described the household conditions of living with their perinatally infected adolescent girls, their needs, and the type of external support they receive.

To address their household economic challenges all the caregivers described the type of support they will need including being supported financially to boost their businesses and those of their husbands so they can support the education of their children. To meet up with the needs of the household, a caregiver combines income with her daughter who does some domestic jobs with her to help the family and to support her education.

Some caregivers and their daughters missed their hospital appointments because they would rather use the little money, they have to provide food in the house than to transport themselves to the hospital. Hence, these caregivers and their daughter sometimes miss their hospital appointments especially their support group meetings. A caregiver described how she had to return to the village because there was no money for food and transport to visit the hospital for her appointments.

Despite all the challenges they face because of their health condition and that of their adolescent girls, some of the caregivers received some financial support from some extended family members and the health facility such as the provision of food support monthly for themselves and their positive children. A caregiver described how she was provided with conditional cash transfer by a Community Based Organization (CBO) to access the health facility for services and ensured her infected children have suppressed viral load.

This study reveals similar findings in other studies about the association between poverty and households infected with or affected by HIV (Tshuma, 2015) and the need to support such households. This becomes necessary as more caregivers living with HIV are having a good life expectancy with less deaths and illnesses due to innovations in HIV treatment and care as compared to previous times (Sherr et al., 2016). However, studies still show that economic hardship, stigma, and unemployment is associated with people living with HIV and so they are forced to live in very impoverished and challenging environments (Sherr et al., 2016). The need for CBOs to contribute to ART adherence and the general wellbeing of ALHIV through the provision of food security, availability of school fees, cash transfer and school feeding programs was highlighted by Toth et al. (2016) and is in resonance with the study findings.

Being HIV positive and caring for their HIV positive adolescent girls in communities that harbors stigma and discriminates against such persons living with HIV only means these caregivers must work in isolation for fear of being rejected or isolated by relatives, friends, and other community members.

The caregivers confirmed the findings from one of the girls on how they experienced stigma and were discriminated against by some relatives when their status was disclosed. By disclosing their HIV status, the caregiver developed resilience by building self-confidence and ensured all those living with her knew their HIV status by testing for HIV. This is a peculiar case as not all caregivers or persons living with HIV are able to recover quickly and build resilience after being stigmatized or discriminated against. Stigma and discrimination are still being reported as major challenges faced by caregivers and ALHIV especially as an hindrance to optimal adherence and reasons for non-disclosure (Osafo et al., 2017).

For fear of being stigmatized and possibly revealing their own HIV status (Wyks & Davids, 2019), the caregivers confirmed that they advised their daughters not to disclose their HIV status to anyone; one of the caregivers told the daughter to say she has been taking her multi-vitamin and not HIV medication when asked by her friends. Telling lies to conceal access to medication was reported by Kihumuro et al. (2021) as one of the negative coping mechanisms used by ALHIV in schools. Another caregiver further confirmed the report of one of the girls on how her mother would not allow her to play with other children for fear of infecting them. Thus, revealing her lack of knowledge about how the virus can be transmitted, and her fear of the daughter being stigmatized. This resonates with Pantelic et al. (2019) about the fact that internalized HIV stigma is associated with guilt, shame and worthlessness and may compromise HIV prevention, care and treatment.

These findings are supported by literature in the study by Galea et al. (2018) who identified sub-optimal relationship between caregivers and their PHIV adolescents, and fear of stigma as the major challenges expressed by caregivers in relation to HIV status disclosure while Kidia et al. (2014) reported the fears of some caregivers about the possibility of ALHIV disclosing their (caregiver's) HIV status to neighbors or persons in the community or school and then get stigmatized or be discriminated against.

While the girls believe stigma and discrimination still thrives in the community, some caregivers agreed with this finding, however, a caregiver believes stigma and discrimination have reduced in some places such as Benue state where she comes from. Adejumo et al (2015) in their study found that HIV related stigma is driven by cultural and religious beliefs in the community and contributes to the high spread of the virus. These beliefs and discriminatory practices prevent PLHIV from accessing prevention and treatment services (Amuche et al., 2017: Kharsany & Karim, 2016).

Metatheme 5: Support System

All the caregivers described other services provided by the health facility that serves as incentives for adherence and reasons for continuous visit to the facility. The health facility provides an empowerment program for adolescents living with HIV such as the payment of school and examination fees, provision of vocational skills accompanied with provision of equipment after training such as sewing machines, hairdressing equipment etc. This is commendable as studies shows that "poverty is the single factor most associated with HIV/AIDS vulnerability, physical and mental ill health, impaired parent-child dyads and child development outcomes" (Lentoor, 2016.

Pg.150). Cluver et al. (2015) reports that social protection intervention helps to mitigate the negative impact of HIV among families, contributes to HIV prevention among adolescents and has the potential of addressing social and economic barriers to accessing treatment, thus improving adherence to ART. Hence the support from the facility helps to alleviate the socioeconomic challenges of these girls and their caregivers.

From the viewpoint of the caregivers, the support group meeting has served as a platform for building resilience and communication skills of these adolescent girls living with PHIV as their caregivers commended the health facility for transport fares and refreshments they provide during the meetings and for the transformation they noticed in their children since they started attending the support group meeting. A caregiver reported that the support group has strengthened the capacity of her daughter on how to take care of her health while another caregiver described how bold and assertive her daughter has become since attending the group meeting.

These findings support those indicated in the literature review about the importance of having a platform for ALHIV to build social cohesion, psychosocial support and to promote medication adherence (Adejumo et al., 2015b; National Agency for the Control of AIDS, 2016).

Metatheme 6: Health Services

The uniqueness of the services provided at the health facility was brought to the fore as all the caregivers could not provide any unpleasant scenario their daughters have experienced at the facility meted on them by any healthcare worker. All the caregivers appreciate the quality of services provided by the health facility staff to them and their adolescent girls and the client friendly attitude of all the healthcare workers. One of the caregivers described the health facility as an “answer to her prayers”. A caregiver commended the health facility for always making drugs available for them even when they are out of stock. These findings are at variance with the findings in literature by Mutambo & Hlongwana (2019) who reported lack of child-friendly environment, inadequate training on pediatric HIV services, lack of formal operational guidelines on the provision of appropriate child-focused HIV services to children and caregivers as major barriers to quality service delivery to adolescent living with HIV in Nigeria.

RQ3. What is the lived experience of healthcare workers regarding Nigerian girls’ access to health services and adherence to ART?

This study also sought to know the experience of healthcare workers who have been providing services to these adolescent girls living with PHIV in the health facility for many years. The peculiarity of this study is that these HCWs are familiar with the health conditions of these adolescent girls and their treatments from childhood to adolescence. Hence, their individual experience in providing care and treatment for this sub-population provides answers to this research question.

MetaTheme 2: Disclosure

The HCWs described the different types of HIV status disclosure they undertake for adolescents living with HIV namely partial, full, and accidental, and caregiver-assisted disclosure. Accidental disclosure is unplanned and happens spontaneously while the caregiver-assisted disclosure involved HCW providing some assistance to the caregiver to disclose the HIV status of her adolescent girl to her. However, many of the disclosure to these adolescents living with HIV occur accidentally. Full disclosure is conducted by the HCWs for adolescents who are 14 years and above because they may be in senior classes in school and may be leaving for boarding schools. Partial disclosure is mostly provided to adolescents who are below 14 years of age.

For the HCWs the following conditions must be considered for HIV status disclosure to adolescents living with PHIV. These includes the caregivers providing consent, the cognitive development of the adolescent, the personality of the adolescent, and the capacity of the HCW.HIV status disclosure to any adolescent living with HIV is not initiated if the caregiver or parents do not give consent. A high cognitive development enables the adolescent to comprehend the disclosure process. A HCW indicated that an adolescent with high cognitive development is likely to know his HIV status without being disclosed to; are more inquisitive and intelligent to device a means of knowing the reasons for taking the ARV or attending the health facility regularly. The World Health Organization recommends that disclosure of HIV positive status to children and adolescents should follow a progressive pattern to accommodate their cognitive skills and emotional maturity (Okolo-Francis et al., 2021). Also, the Nigeria National Guidelines for Pediatric HIV/AIDS Treatment and Care recommends that the disclosure process should consider among other factors, the cognitive ability of the child/adolescent and the consent of the parent/caregiver (Okolo-Francis et al., 2021). The personality of an adolescent is a contributory factor to HIV status disclosure as indicated by one of the HCWs who informed that for a talkative child or adolescent, the HCWs are careful about the information provided to such a child or adolescent during the disclosure process.

A major challenge to HIV status disclosure to adolescents living with PHIV as indicated by the HCWs, is the refusal of some parents to give consent or allow their adolescents to be disclosed to for fear of being stigmatized because the parents have self-stigma and are afraid the child might disclose his/her status in public. Another challenge is the fear of uncertainty by the caregivers who are not sure of the actions the child or adolescent may take after being disclosed to, whether the child will keep the information confidential. Also, some caregivers feel their adolescent girls are not matured enough to be disclosed to and so they decline disclosure. In the study on caregivers' experience with caring for a child living with HIV/AIDS in Ghana by Atanuriba et al. (2021), non-disclosure to children with HIV was hampered by the caregivers believing that these children were not matured enough to be disclosed to and pray that the day should not come, and that stigma and discrimination was also the factors contributing to non-disclosure.

Post disclosure outcomes by adolescents with PHIV includes depression, trauma, unhappiness, and many unanswered questions in the minds of these adolescents as indicated by the HCWs. Some of these questions includes how they got infected and if they do not get a good answer from their caregivers, they approach the HCWs. Some of the adolescents secretly visit the hospital for confirmatory HIV test after being disclosed to as they doubt their status because they do not look or feel sick. However, the mother-daughter bond prevents the adolescent girls from displaying negative (violent) reactions to their mothers after HIV status disclosure compared to the mother-son bond. This is because mothers are known to pamper their daughters compared to the adolescent boys.

However, reactions from some adolescents after HIV status disclosure may turn violent and this frightens the caregivers who often run to the adherence counsellor at the health facility for assistance. This is at variance with the finding from Okolo-Francis et al. (2021) who reported that caregivers/parents prefer to disclose to their male children compare to their female children.

The HCWs informed that caregiver's disclosure of the HIV status of their adolescents to them is the best as compared to HCWs disclosing to the adolescent girls. This is also the preference of the adolescent girls and that the HCWs should only be invited if the caregivers need assistance. This supports many studies conducted to ascertain who is most suited to disclose the HIV status to an adolescent who is HIV positive, the caregiver or the healthcare worker? Ngeno et al. (2020) reported that most persons prefer the caregivers to disclose to the adolescents with HIV. However, findings in the literature review also indicates that due to the accuracy of the information the HCW may provide, adolescents with PHIV prefer the HCWs to disclose their HIV status at the clinic to them compared to their caregivers (Kidia et al., 2014).

Prior to HIV status disclosure to the adolescents, the adolescent girls were very curious about the drugs they were taking and the reasons behind it. Hence, they resorted to different personal innovations including using the internet to search for the names of the drugs they were taking. This led to them to know their HIV status since their caregivers were also hiding the drugs from them and was not forthcoming on the reasons. The study provides the pre-and post-disclosure experience of the adolescent girls which is at variance with Okolo-Francis et al. (2021) who reported that in their review of literature on disclosure experiences and challenges among children and adolescents living with HIV/AIDS in Nigeria, none of the studies assessed pre- and post-disclosure activities and their association with ART adherence.

Metatheme 3: Antiretroviral Therapy

In managing the health condition of the adolescent girls with PHIV, the HCW informed that the health facility provides two drug regimens which are once-a-day and twice-a-day regimens. The twice-a-day regimen may have been provided at childhood but changed to once-a-day regimen which is the preferred as the child grew to adolescence with a weight of about 30kg. The preference for the once-a-day regimen is because it does not require much supervision by the caregiver and does not interfere with the schooling of these adolescents as it can be taken as early as 6 am or 7 am before school. However, some adolescents living with the virus are on the twice-a-day regimen. This finding is supported by Foster et al. (2020) on the preference for single-tablet/once-daily dosing which is reported to be associated with improved adherence. There are other drug regimens such as the first- and second-line regimens with more ALHIV on the second line regimen than those on the first line regimen. Some perinatally infected adolescents who were diagnosed at the age of 8 years or 10 years are placed on first line regimen.

A major challenge to medication adherence as indicated in the study is that some of these adolescent girls are tired of taking the drug for such a longtime. Pill fatigue which is characterized by stress and the monotony of constant pills swallowing, was reported by Tshuma (2016) as one of the challenges adolescents with PHIV face in managing their health condition.

The study also identified that adverse drug side effects among these adolescent girls are not so common because the health facility employs the strategy of identifying the drug causing the adverse reaction and replace it with a better one. Also, the health facility ensures the best regimen from childhood is provided according to their growth from the time of ARV initiation. However, should there be any drug reactions, the HCWs address these at the facility especially for those that have lasted for more than four days by pulling out the offending drug and replacing with a better regimen. To ensure adverse drug reactions are monitored, the facility ensures that once any ALHIV is placed on ART, a follow-up home visit is conducted to address any adverse drug reactions that may occur. The adverse drug reactions may also have been caused by excess dosage of a particular drug such as Nevirapine which causes hepatitis or efavirenz which causes nightmares.

Although Flynn & Abrams (2019) indicated that some persons living with PHIV may be at risk of some diseases because of long-term use of some regimens, the findings in this study indicates that any drug likely to cause adverse effects were identified and replaced with better ones by the Clinicians in the health facility. Hence, adverse side effects are not common.

The study identified common health challenges associated with these girls to includes malnutrition, body rashes, diarrhea, malaria, typhoid, cerebral palsy (rare). Others include malaria, toilet infection especially for those in boarding schools, diarrhea because of the quality of water they take, cough which is noticed among the little ones and those health challenges that may occur due to immunological failure. The study also identified other health challenges such as Papular pruritic eruption, vaginal candidiasis, Pulmonary Tuberculosis (rare) and chronic diarrhea in older ALHIV because of the second line regimen being used. It is important to note that some illnesses are drug induced such as the hepatitis which was common when using Nevirapine containing regimen; rare and minor skin eruption was also due to Nevirapine. There are several studies indicating the different health problems associated with adolescents with perinatal HIV infection which are due to long-term HIV infection and its treatment (Vreeman, Scanlon, McHenry, & Nyandiko, 2015; Tshuma, 2016; Flynn& Abrams, 2019). To address opportunistic infections, the health facility is supported by some partners to provide prophylaxis with other drugs to address opportunistic infections and other ailments among ALHIV.

To ensure adolescents living with PHIV adhere to their medication, the health facility engages the services of some healthcare workers called “Activists” who are living with HIV and act as role models to provide home-based care to these adolescents.

The study found that adherence is better for ALHIV whose both parents are also living positive and alive than those with a parent who is HIV positive and alive. Also, adherence is better for those ALPHIV whose HIV status have been fully disclosed to them.

During the COVID-19 lockdown in the country, the health facility developed a strategy of providing drugs to clients who could visit the hospital for their drug pick-up. Those who were not able to visit the hospital were tracked on phone to ensure they pick up their drugs from the nearest health facility to them. Where it was not convenient for an adolescent with HIV to pick up her drugs in the nearest health facility, the facility ensured drugs were taken to these persons in their homes. Those who travelled out of the state and never returned were transferred to other health facilities to continue with their treatment.

The study found that because some of these girls look healthy for adhering to their treatment, they sometimes deny their status and stop taking their medication. Some are very playful and as a result forget to take their medication while some caregivers assume that these girls are old enough manage themselves unsupervised, but this is not the case. Therefore, constant follow-up and supervision are needed to ensure they adhere to their medication.

The study observed poor adherence for PHIV adolescents who have lost a mother but have a living father, and the same goes for those whose parents are dead but live with relatives. This is because the intensity of supervision and care by these relatives is poor and so extra counseling for the child, adolescent and caregiver will be needed. This buttresses the importance of the mother-child bond in promoting adherence among adolescents with PHIV since they both share common chronic health condition (Lentoor, 2017).

Adherence challenges for ALHIV in boarding schools were highlighted in the study (see table 5) as being difficult and fueled by the fear of stigma and the absence of a caregiver to provide the necessary supervision during medication intake. To address this, the status of the ALPHIV must be disclosed to someone in the boarding school who will act as the caregiver. Another challenge is that the school timing is at variance with the time the ALHIV takes their drug; an adolescent's time for taking her medication for over 10 years may be 7 am in the morning at home when in day school but at 7 am in the boarding school, the adolescent must be at the assembly ground. Thus, making it difficult for the adolescent to take her medication on time. There are several similar studies confirming the difficulties encountered by adolescents with HIV in adhering to their medication in school settings especially in boarding schools (Adejumo et al., 2015; Folayan et al., 2015; Galea et al., 2018; MacCarthy et al., 2018).

To address the challenges of the girls not adhering to their medication, the study found the following strategies adopted by the facility to assist these adolescents improve adherence. These includes referring defaulting ALHIV and those newly disclosed to, to the adherence class (where they meet with the Adherence Counselor to teach them what to do and how best to improve their medication intake), and compulsory viral load assessment for all ALHIV which helps to determine if the adolescent has been taking his/her drugs. A high viral load indicates that the adolescent has not been adhering to medication. Other strategies include Direct Observation Therapy (DOT) which involves a HCW regularly visiting the home of ALPHIV to ensure adherence by observing when the adolescent takes his/her drugs, and pill count assessment at the pharmacy. The number of pills an ALHIV brings to the pharmacy at the health facility during clinic appointments determines if the ALHIV is adhering to medication as expected. Martelli et al. (2019) reported that there are numerous literatures indicating the use of Pill count assessment to determine the proportion of adolescents with HIV with optimal adherence to medication who are also expected to have suppressed viral load. However, the possibility of defaulting ALHIV discarding pills to hide non-adherence was reported by Okatch et al. (2017).

To provide an understanding of the adherence challenges at the home of these adolescent girls to the HCWs at the facility, the caregivers are expected to escort their children to the facility to provide vital information to guide the HCWs to take informed decisions about the health condition of these adolescents. Such includes understanding the reason or reasons caregivers do not allow their adolescents not to take their drug when there is no food at home. Escorting their ALHIV to the health facility during clinic appointments also provides the opportunity for the HCWs to clarify some information these adolescents may have provided about their personal challenges at home.

To address the problem of lost-to-follow-up by ALHIV, the HCWs tracks the ALHIV through phone calls to know the reason or reasons for the missed appointments. This is followed by a second call after 14 days depending on the response from the adolescent, and if no favorable response, then the call is repeated after two months followed by a follow-up visit to the home of the adolescent. If the situation remains the same, after 90 days, the ALHIV is declared lost-to-follow-up.

Metatheme 4: Stigma

The study found that ALHIV are treated with love and care and held in utmost regard in the health facility by staff. This is designed to assist them to continue with their treatment and continue to visit the health facility. To ensure no staff stigmatize or discriminate against any of the ALHIV, the health facility has a policy against stigma and discrimination and all staff have been trained and re-trained on new developments including building capacity on how to address HIV stigma and discrimination. Thus, no case of stigma and discrimination against ALHIV have been reported so far in the health facility as reported by the HCWs who participated in the study.

This finding is at variance with the findings in literature by Amuche et al. (2017) who reported that stigma and discrimination have prevented HIV patients from accessing healthcare in sub-Sahara Africa. The health facility in the study reported successes in addressing stigma and discrimination among the HCWs and other staff. This is one of the reasons the health facility is experiencing the influx of more positive persons accessing services at the facility.

Metatheme 5: Support System

The health facility provides a forum for all adolescents living with HIV to meet monthly to discuss issues of common interest as a support group. However, with the introduction of a more structured adolescent support group known as Operation Triple Zero, OTZ (zero missed appointment, zero missed drug, zero missed and zero viral load) by an implementing partner to improve adherence and achieve viral suppression, more ALHIV 14 to 20 years have improved adherence and viral load suppression. ALHIV who attend the support group meetings also benefit from skills acquisition programs such as the making of soaps, shoes implemented by the health facility specifically for them. The finding in the study linking viral suppression among ALHIV receiving ART in the health facility is similar to the finding by Mark et al. (2019) who reported a seven-fold increase in viral load suppression rate among ALHIV attending facility-based peer support group (like the OTZ) in Kenya. To sustain the support group and make it less donor dependent, the health facility has set-up a business venture to be managed by the adolescents who are members of the support group.

As a faith-based health facility, the facility funds the treatment and care of indigent ALHIV including girls as this supports the facility's mission of serving the sick and less privilege. The facility also provides food support and food supplements monthly to malnourished children and adolescents living with HIV to improve their nutritional status. As part of the facility's social protection scheme, it also provides food support to some caregivers living with HIV, and this has been the practice for some years. To provide many of its services for free especially to PLHIV, the health facility enjoys some external support from sister organizations overseas, international donors and some local partners.

Metatheme 6: Health Services

In the study, findings show that the health facility provides services for free, and no user fees are charged for ALHIV; their drugs, treatment, food are provided for free. This enables more ALHIV access services at the facility than when fees were charged, and more children and adolescents were missing their hospital appointments. Ahonkhai et al. (2020) reported that the introduction of user fees in Nigeria because of funding cuts by donors, is a crucial barrier for patients to access ART and so the removal of user fees creates more access and retention in care. Thus, supporting the findings of this study.

All HIV services provided at the facility are summed up as comprehensive ART which includes adherence counseling, treatment preparation classes, clinic consultation, laboratory monitoring, pharmacy dispensary and DOT clinic for those who may have

Tuberculosis, support group meeting, food support especially for those who are malnourished or other social reasons.

Findings also indicates that the same model of care is provided to adolescent girls with perinatal and behavioral HIV; separate HIV services are not provided to the two classes of ALHIV (BHIV and PHIV). For stable clients including ALHIV, the health facility provides multi-month scripting (MMS) whereby these ALHIV are provided three months drug supply to reduce the number of times they need to visit the health facility. In a bid to encourage adherence among ALHIV, the facility also provides different drug pick-up options to PLHIV such as family drug pick up, group drug pick up and fast track drug pick up. The health facility collaborates with other health facilities in the Federal Territory to ensure children and adolescents living with HIV benefit from services not provided by it. Hence, children and adolescents with HIV benefit from such inter-facility collaborations especially during the COVID-19 lockdown.

Families who are living with HIV are given the same appointment dates and are provided services on the same day as a family in the health facility. This is because, the health facility implements a family centered model of care for children and adolescents living with HIV and not a specialized clinic for children, adolescents and another for adults living with HIV. This finding aligns with Khumalo et al. (2020) who reported the acceptability of family-centered model of care for HIV positive children in Eswatini. The implementation of the family centered model of care as compared to the standard model in Eswatini assisted in strengthening family bond, encouraged family members to disclose their HIV status and assisted family members in supporting each other in adhering to their medication and treatment (Khumalo et al., 2020).

Since the health facility does not have specialized clinics separately for children and adolescents living with HIV and adults living with HIV, transition of the ALHIV is done through adjustment of their drug regimen to conform with their new weight. The transition process also involves the HCWs communicating directly with these adolescents instead of going through their caregivers or parents. For those who are fully aware of their HIV status, they are referred to the adherence class and can access services directly and discuss other private matters that may not have been discussed in the presence of their caregiver by the HCWs. The advantage of this model of transition is the that the same healthcare workers these adolescents are familiar with from childhood, are the same providing services to them in their adolescent and adult life. Hence, the individual challenges of these adolescents are factored into the adult transition process and the type of care provided to them in the adult age by the same HCWs. This is at variance with findings in the literature review which indicated the challenges adolescents with PHIV infection face when transitioning to an adult clinic where they receive comprehensive HIV treatment services and build trust over many years with the clinic staff (Cruz, 2015; Folayan et al., 2015; Tepper, Zaner, & Ryscavage, 2017). In the case of the findings in this study, the trust built over the years between the ALHIV and the HCWs is sustained as the ALHIV continues with the same HCWs from childhood in their adult age.

Findings from the study shows that the barriers to service delivery experienced by the HCWs in the health facility are in two folds namely the ones from the healthcare provider (healthcare provider related) and those caused by the adolescents (patient related). The healthcare provider related challenges include reagents, commodities, and drug stock-outs which may be due to some logistic reasons, delay in supply or stockout in the market which could be from the central logistic system. To address the problem of drug stock-out, the health facility had to adjust the regimen of the ALHIV to provide what was available pending when new supplies arrive from the Central logistic system.

The challenges from the ALHIV (patient related) that affects the HCWs ability to provide services, is the inability of some of them to visit the health facility for their hospital appointments due to lack of transport fare since they live far away and are dependent on their caregiver/parents who are mostly poor. This finding was highlighted by Inzaule et al. (2016) as one of the challenges experienced by caregivers of ALHIV. Sometimes, these caregivers cannot afford to provide the transport fares for these ALHIV and so they miss their appointments. The option of reaching these adolescent girls via the telephone to share some vital information with them is challenging as some of them do not have cell phones. Hence, the HCWs may have to talk to them through their caregivers who are the only ones with the cellphones. This has contributed to the number of lost-to-follow-up and poor adherence in the facility.

The study also shows that the health facility provides services such as education support, skills acquisition, and empowerment programs to very few and not all ALHIV accessing services at the facility due to some financial constraints. Because the hospital appointment card is kept with the caregivers or parents, if the caregiver does not remember the appointment days, the adolescent girls may miss their appointments. This has contributed to the number of miss appointments and poor adherence in the facility. This highlights the fact that the girls are dependent on the caregivers, and this could contribute to them missing their appointments.

Another challenge faced by the HCWs is that the facility does not provide reproductive health services for the girls in the facility as a Faith-based health facility, This is against its mission and vision. This has been a challenge as the health facility does not offer services such as barrier contraceptives, and condoms etc to these adolescents despite their enquiries about sex and sexual practices. For those in need of such services, they are referred to government own facilities where such services are provided.

RQ4. What are the perceptions of Nigerian girls with perinatal HIV, their family members and healthcare workers regarding how HIV services for adolescent girls could be improved?

In this study, all the girls, caregivers and HCWs provided varying recommendations on how service delivery for adolescent girls with PHIV can be improved from their individual experiences.

Common among the adolescent girls with PHIV are a list of services they want the health facility to continue to provide for them. These includes viral load monitoring, adherence counselling and support group meetings with more ALHIV attending. Others includes the need to intensify follow-up activities to ALHIV in boarding schools and others who are not adhering to their medication, and support adolescents living with HIV with transport fares to keep up with their clinic appointments. Critical to these girls is the need for the facility to waive the viral load assessment fee for caregivers/adults (their parents) living with HIV to allow more persons to access treatment at the facility.

Although all the caregivers commended the health facility for the type and quality of services provided to adolescent girls living with HIV, all the caregivers who participated in the study made some recommendations to improve service delivery. These includes conducting a needs assessment for all ALHIV to identify their specific needs and to tailor their services to such needs of these adolescents, have more HIV positive adults access HIV services at the health facility, the removal of user fees and viral load assessment fees charged by the health facility to adults. Others includes the continuous provision of free ARV and drugs for other ailments such as fever and malaria and the resuscitation of the home-base care component of their services to help address treatment challenges they encounter in their homes.

Improving service delivery for adolescent girls with perinatal HIV at the health facility was also a concern of the health care workers who participated in the study. Their recommendations include the continuous provision of the counselling component of the services provided by the health facility, provision of sufficient drugs to address opportunistic infections (IOs) among clients who refuse to access their drugs from other facilities when referred and to continue to provide vocational skills training for ALHIV who are out of school because they cannot afford to pay for school fees to access formal education. Others includes, to continue to provide quick turnaround time for the ALHIV during clinic appointments, to scale up her HBC activities as this was scaled down due to some financial challenges encountered by the facility and the continuous provision and scale up of food support to all ALHIV and their caregivers since only limited number of ALHIV and their caregivers/parents benefit from such support. To reduce the incidence of malaria by ALHIV, a recommendation that the facility should be supported with mosquito nets was made, and that the facility should continue to support the adolescent support group meetings as a platform to encourage optimal adherence and viral load suppression.

Limitations of Study

There were some limitations in this study. Notable among them was insufficient number of adolescent girls with BHIV to participate in the study. This restricted the research participants to adolescent girls with PHIV. Also, all the adolescents who participated in the study were female which limits the study outcomes to their experience of living with perinatal HIV when compared with the inclusion of the male gender in the same health facility. Another limitation is that the study was conducted in a faith-based health facility which does not provide other adolescent services such as sexual reproductive health because of their beliefs. It will be interesting to know the outcome of similar study if carried out in a government health facility which provides full complements of services. There might be some limitations on the accuracy and validity of my findings because I collected and carried out the analysis alone manually with some advice from my Chair although I maintained impartiality during the rigorous analysis of the data.

Using purposive sampling in the study means that only the perspectives of a few adolescent girls who volunteered to share their experiences in the study was reported and not all adolescent girls with PHIV and receiving HIV services in the health facility. Thus, the study outcomes cannot be generalized as the experience of all other adolescent girls with PHIV receiving HIV services in the same health facility.

Recommendations for Future Research

The literature review in chapter two reveals research dearth in PHIV among adolescents in Nigeria. This study provides some knowledge on the experiences of adolescent girls living with PHIV, their caregivers and healthcare workers who provide services to them in a faith-based health facility. There is the need to conduct more research on the experiences of adolescents living with PHIV as well as l BHIV in Nigeria. It will be interesting to know the experience of adolescent girls with PHIV who come from economically stable households as compared with the poor households of the adolescent girls like the ones who participated in this study. Thus, seeking to understanding the influence of poverty in the households of this sub-population. This study also reveals gender dynamics in the relationship among the participants by showcasing the mother-daughter bond as both are infected with the same chronic disease (HIV) as compared to the mother-daughter bond where only the daughter is infected with HIV (where the adolescent girl is behaviorally infected, and the mother is HIV negative). Since HIV status disclosure is the pre-requisite for adherence to medication and treatment, the reaction to HIV disclosure by a male adolescent with perinatal HIV infection should be explored. This becomes imperative as this study only reveals the reactions of adolescent girls with PHIV to HIV status disclosure. Therefore, by changing future research participants to adolescent males with PHIV will not only address the dearth in research but could provide a different understanding of how adolescent boys with PHIV would react to HIV status disclosure. I will therefore recommend that similar research be conducted in different states, other private and government facilities in the country. This will provide rich knowledge on the experiences of adolescents living with HIV in Nigeria and guide the development of context specific intervention strategies to address their needs. The study also indicates a low comprehensive and correct knowledge of HIV/AIDS among the adolescent girls. A quantitative study may therefore be needed to know what the level of the comprehensive and correct knowledge of HIV/AIDS among HIV positive adolescents is, and the level of awareness of HIV/AIDS as compared with the comprehensive and correct knowledge of HIV/AIDS among adolescents generally. This becomes imperative as having the accurate knowledge of HIV/AIDS among adolescents empowers them to prevent risky behaviors and to seek for the right service.

Implications for Social Change

My resolve to undertake this research is guided by lessons learned from the article by Kezar (2014) which fortunately is further supported by the findings of the study. Kezar (2014) suggest that a multidisciplinary approach may be needed to resolve complex problems by engaging multiple stakeholders through collaboration or partnership which may require different expertise to address. Thus, for positive social change to occur, one need to understand the experiences of the adolescent girls living with PHIV and the social relationship with their caregivers and the healthcare workers who provide services to them. The findings of this study which shows that the challenges experienced by adolescent girls living with PHIV in accessing HIV services in Nigeria extends beyond them and includes other key players in the SEM, establishes the basis for positive social change across the established patterns of interaction.

To achieve the social change, the findings of this study will be shared with the health facility where the research took place to provide more knowledge about the lives of these girls and their caregivers who are also HIV positive, develop an appropriate model to educate these adolescents with appropriate information on PHIV, prevention, care and treatment of HIV, improve on their service delivery model, provide more adolescent friendly services including strengthening the current adolescent support group, and further encourage them in their quest to make life better for them. The findings in this study can also be used as a resource document to guide the development of a strategic framework to address the plight of adolescents with PHIV. The study brings to the fore the need to encourage HIV status disclosure by caregivers to their adolescents and not healthcare workers to the adolescents. This emphasizes the importance of building the capacity of caregivers early and addressing their fears as fundamental to achieving medication adherence and subsequently improve viral load suppression. The burden of providing for these adolescents by the caregivers is enormous and weighs heavily on their health, finances, and psychological wellbeing as they are also HIV positive and manage their health condition with very poor domestic economy. This negatively impacts the mother-child dynamics and their households and greatly affect the development outcomes in the adolescent. Hence, designing an intervention with focus on the mother-child dynamics to address these challenges as well as providing some household economic support will assist in alleviating these challenges. Living with the fear of being stigmatized and discriminated against was evident in the study and so educating the public or creating more awareness on the prevention, care and treatment of HIV will help in addressing some myths and misconceptions about the virus that are fueled by culture, religion and other factors.

Supporting innovations that further identifies more HIV positive children and adolescents such as the HIV Self testing using oral-fluid kits and linking them to care will be a major contribution to HIV epidemic control as more of these persons will live healthy and grow to adulthood.

The study will also be shared with the Federal Capital Territory Health Research Ethics Committee which provided ethical approval for the research to be conducted in the FCT. This will create the opportunity for government and other key stakeholders to have access to it and possibly use its findings in other research and HIV interventions for adolescents living with HIV.

Conclusion

This study shows that adolescent girls with PHIV are a unique sub-population that need special healthcare and HIV sensitive social protection interventions as they are being confronted with various developmental challenges and HIV-related stigma in the society. The different metathemes and themes that emerged from this study clearly shows the experience of adolescent girls with perinatal HIV in accessing healthcare services and managing their condition which includes adhering to medication, the experience of their caregivers in managing the health condition of the girls and the experience of the healthcare workers in providing care and treatment. I have provided below, a synopsis of the study findings.

Pre and Post HIV disclosure experience of the girls

The study highlights the pre- and post-experiences of these girls in disclosing their HIV status, accessing services, and adhering to ART. These girls were often sick and frequenting the hospital with their mothers prior to their diagnosis. They did not have the knowledge of the nature and type of the illness in them when they were initiated on ART. Their HIV status was disclosed to them by their fathers or mothers which gave rise to many worries and questions such as why and how they got infected. Their diagnosis prompted their caregivers to also take the HIV test and then discovered their girls were infected by them.

Disclosure Challenges by HCWs and Caregivers

From the context of the HCWs, the major disclosure challenge is consent decline by caregivers for the HCWs to commence disclosure, while the caregivers' major concerns were the fear of not knowing how the adolescents would react and the issue of the child/adolescent not keeping the information confidential by not telling others in public. Hence, the children/adolescents were often advised by the caregivers not to disclose their HIV status to anyone.

The Girls reasons for adhering to ART

Long-term adherence to ART for the girls has been characterized by the need to have their viral load reduced to stay alive, the fear of developing AIDS and dying and the need to keep their future partners and family members free from HIV infection.

Factors Promoting Access to Services and Adherence to ART by HCWs

The free and friendly family centered healthcare services, for all ALHIV following the removal of user fees and all other fees which has increased the uptake of HIV services, the introduction of once-a-day regimen and not the twice-a-day regimen and the provision of transport fare and refreshment for those who attend the support group meetings as well as some social protection schemes amongst others have been a major boost from the health facility for these adolescent girls who now have their viral loads suppressed and hopeful of achieving their life's dreams.

The social protection program for ALHIV provided by the facility such as providing food support and education support to adolescents and their caregivers in need and vocational skills training for out of school adolescents with HIV and the provision of free equipment after their training have become best practice by the health facility to better the lives of these girls and their caregivers and to retain them in treatment and care.

Reduction of Adverse Drug Reactions

One of the unique elements of this study is the finding that the health facility has been able to drastically reduce the adverse drug reactions (ADRs) among these adolescents with PHIV who have been on long-term care by selecting the best regimen from childhood, adjusting excessive dosage, and replacing any offending drug with a better one. This has improved adherence and retention in care and invariably, the health condition of these adolescents. This is appreciated by the girls and their caregivers and a welcome innovation which is at variance with other findings in literature as indicated in the study.

Unique Transition to Adult Care Model for the Girls

Implementing a transition to adult care model that includes these adolescents being seen by the same medical personnel from childhood to adult care over the years, enables the HCWs to factor their childhood and adolescent challenges into adult care and provide appropriate drug regimens. This transition model has helped to build trust with the same HCWs staff over the years and has improved access to services and retention of these adolescents in care.

Reviving the Home Base Care Activities of the Health Facility

The household vulnerability index shows that these adolescents and their families infected or affected by HIV reside in resource limited settings which negatively impacts on the caregiving ability of the caregiver specially to provide optimal care. Therefore, reviving the home-based care component of the services by the health facility as recommended in the study will provide some household-based delivery of support to the caregivers and the adolescents with PHIV.

Strengthening the Referral System

Strengthening the referral system at the community level to provide linkage between the community-based organizations providing social protection and psychosocial services (including building the parenting skills of the caregivers and addressing the child behavior challenges of the ALHIV), and the health facilities providing ART is an ideal strategy that emanates from the social network analysis. The social network allows participants of a social system to arrive at a network of relations and new way of operating.

Adolescent Support Group as a Major Factor Promoting Adherence among the Girls

The structured facility based OTZ support group provided a unique opportunity and platform for social cohesion, build resilience and coping skills as well as providing the necessary support for adherence and viral load suppression. Hence the need to continue to support this facility-based peer group platform by the health facility cannot be overemphasized.

Resilience of the Girls as a Factors Promoting Access to Services and Adherence to ART

The study also highlights the resilience of the girls to stay healthy, and the contributory role the mother-child dynamics plays in assisting the adolescent girls to build resilience, and provide the much-needed psychosocial support (love, care, and protection for better cognitive, emotional, and spiritual wellbeing) to help them secure confidence to explore their environment, grow and develop the necessary life skills needed to manage themselves including adhering to their medication which is key to attaining viral suppression.

Factors Hampering Access to Services and Adherence to ART by the HCWs

The healthcare worker-client dynamics reveals the healthcare-provider related challenges as well as the patient-related challenges encountered at the health facility to address the needs of these girls. For example, challenges such as the health facility rationing the drugs to ensure persons with HIV have their drugs for at least a month during drug stock-out pending when sufficient drugs are supplied to the facility, and the girls with suppressed viral loads playing pranks with their medication because they look and feel healthy and so discontinue taking the drug (drug holiday) have been major concerns for the HCWs. Other challenges identified by the study include pills fatigue (exhaustion due to long-term commitment to ARV) despite changing their drug regimen from twice-a day to once-a day regimen.

Lack of Transport Fares to Access Services at Health Facility

Although the adherence and viral load of the adolescent girls in the study are good, lack of transport fare for these girls to access services during clinic appointments is a threat to these achievements. Thus, addressing the household economic challenges identified in the study by empowering the caregivers to provide the necessary funds such as transport fare for them to access treatment at the facility is necessary to sustain these results. The health facility's differentiated service delivery such as routine viral load monitoring, and the provision of multi-months scripting for stable adolescents which helps to reduce the number of times they visit the hospital for drug pick-up will assist in reducing the transport fare burden and should be sustained.

The Mother-Child Bond as a Factor Promoting Access to Services and ART for the Girls and Caregivers

The urge to stay clinically healthy by adhering to their medication to live their dreams and the different personal strategies they adopted with their caregivers to achieve this such as taking their medication together and supporting one another are well documented in the study and is a model that enhances the parent-child communication and relationship. Thus, the need to support the mother-child bond as a family since they share common chronic health condition should be the concerns of all stakeholders. This is not only fundamental to the success of any intervention proposed for this sub-population but helps to address other issues or challenges that may arise from their long-term commitment to ART. To further encourage this bond, the girls have requested for the removal of the user fee and viral load fee charged by the facility for all the caregivers/adults with HIV.

Low Comprehensive and Correct Knowledge of HIV/AIDS

The study identified low comprehensive and correct knowledge of the prevention, treatment, and care of HIV/AIDS among the girls. This is a challenge to adherence and uptake of HIV services and so there is the need for these adolescent girls to have a good and correct knowledge of the prevention, treatment and care of HIV/AIDS to enable them to make informed decisions about their health.

Poor Menstrual Hygiene among the Girls

Another unique finding in this study is the poor menstrual hygiene management that is common with these adolescent girls with PHIV which is further threatened by the low socioeconomic status of their caregivers/parents. For positive social change, interventions that promotes or integrates good menstrual hygiene management among adolescent girls with HIV is a right step in the right direction needed to address this challenge.

Lack of Sexual Reproductive Health Services for the Girls

Although the facility as a faith-based organization, does not offer reproductive health services but refers the girls to government facilities for such services, this underscores the need to ensure the availability of such services to this sub-population when providing comprehensive HIV services.

HIV related Stigma as Hinderance to Access and Adherence to ART

The study identified HIV-related stigma as a major obstacle to adherence for ALHIV and their caregivers. Hence, addressing HIV related stigma and discrimination through the development and implementation of context and culturally sensitive interventions in schools, churches, mosques, and health facilities will help to reduce the incidence of stigma and discrimination among HIV infected persons. School based interventions will be most ideal to target HIV related stigma-reduction experienced by ALHIV as more students will be reached as compared to having a community-based intervention.

Finally, the effective implementation of the prevention of mother to child transmission (PMTCT) of HIV will ensure that no child is perinatally infected with HIV, thus bringing an end to vertical transmission of HIV in Nigeria. With the availability and adherence to ART, no child with PHIV should die of AIDS. Therefore, intervention focus for all stakeholders which should integrate HIV sensitive social protection schemes as found in the study, should be to support and promote access to health services and adherence to ART for adolescent girls living with PHIV. The intervention should commence from the individual and caregiver levels as an inseparable entity (family) and should include the healthcare providers level as pivotal to them staying virally suppressed and clinically healthy.

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Appendix A: Interview Protocol - Adolescent Girls

Category	**Adolescent girls with Perinatal HIV**
Introduction	I am Joseph Inyang, a Ph.D. student from Walden University working on the dissertation topic "Perspectives of Girls, Families, and Healthcare Workers on Accessing Services for Adolescents with Perinatal HIV in Nigeria." This means "How adolescent girls like you living with HIV can receive the services they need. What is their experience living with HIV, the drug they always take, and the experience of their parents/guardians and health workers who take care of them"? I hope that the answers you provide to the questions I shall ask you will help Doctors, Nurses, and other health care workers, parents, and family members best provide for and take care of adolescent girls living with HIV like you. The results of this research should improve how you take your HIV medications and how best you can be helped to overcome the challenges you face as a result of HIV so you can live healthily and achieve your life's dreams. I appreciate your decision to participate in this study and ask you some questions. We anticipate this interview will take 90 minutes of your time. During the interview, I will be recording the session with an electronic recorder. All information gathered will remain confidential as your identity will not be known to anyone or mentioned in the study. Do we have your permission to record the interview to ensure that I remember what you say? "YES/NO." You do not have to answer any question that you do not want to. Please note that you may stop the interview at any time. You are free to leave the interview at any time without prior notice, and you will not be penalized. If you have questions, you can ask me.
	Preamble
Questions	Let's start by telling me a bit about yourself, like where you live, the school you attend or attended, and what you hope to be in life (your aspirations/dreams)?
	Knowledge of HIV/AIDS
1	Can you tell me the meaning of HIV/AIDS?

2	How is HIV passed from one person to another?
3	What causes HIV?
4	How can HIV be prevented?
	Knowledge of HIV Status
5	How did you find out about your HIV status, and when was this?
6	What were your feelings and thoughts when you discovered you were infected with HIV?
7	Did you seek help, e.g., from a relative like an auntie, a friend, or counselor? If yes, please tell me about it
	Disclosure
8	Tell me how you come to disclose your HIV status and how long did it take you?
9	Why did you have to disclose your HIV status?
10	How did you feel after disclosing your status?
11	Who did you disclose to, and what was this person's reaction?
12	How did you feel about this person's reaction?
	Health Care
13	What was your first experience like when you visited the health facility and placed on ART? (*probe for any unpleasant experience with the health facility staff*).
14	Did you find the treatment at the health facility helpful? Can you share your experience with me?
15	How often do you visit the health facility for treatment or medication refills?
16	Please explain how you think health services for adolescents with HIV can be improved at health facility?
	Treatment (ART)
17	Please tell me about any medicines that were prescribed for you (probe for ART if not mentioned)
18	Can you tell me how long you have been on ART?
19	Can you explain the reason you have to take your medication as prescribed?
20	What are the challenges you experience when you take your medication? (*Probe for side effects*)
21	How do you manage the side effects of the medication?
22	What challenges do you experience when you do not take your medication as prescribed?
23	What are the reasons for not taking your medication (for missed medication)?
24	Do you visit the health facility to collect your medications yourself? If NO, why not? Does someone else help you with this?

25	If someone else collects your meds, what is your relationship with this person?
26	Are you being supervised or reminded to take your medication? *(probe; ask for the person)*
27	What other challenges do you have with your treatment?
28	What are your thoughts about the longtime experience of being on ART?
	Everyday life
29	What are your daily needs living with perinatal HIV, and how do they affect your self-esteem?
30	How do you address these needs daily?
31	What assistance do you think your parent/guardians would need to help you manage your illness?
32	Are you in a sexually active relationship? If yes, can you share your experience disclosing your status to your partner? Do you practice safe sex with your partner (use of a condom)?
33	If NO, can you share your reasons? (Probe for fear of transmission of HIV to partners or unborn baby)
34	What would be your reasons/s for being in a sexually active relationship? (Probe for peer pressure, plans to have children-motherhood desire)
	Social Support
35	Do you have any support or assistance to help you with these challenges? Who or what is the support system? (Probe for family, friends, health care worker, adolescent support group, community).
36	Were you provided enough information about HIV prevention and treatment at the health facility?
	School/Community Experience
37	Have you experienced any stigma and discrimination in school about your HIV status? If yes, can you share your experience?
38	How do people in your community assess people living with HIV, especially adolescents? (Probe for stigma and discrimination and gender; ask for any specific experience)?
39	Is there anything else you would like to share with me before we end the interview?
Closing statement	Thank you for your patience and time.

Appendix B: Interview Protocol – Caregivers

Category	**Caregivers/Parents/guardians of adolescent girls**
Introduction	I am Joseph Inyang, a Ph.D. student from Walden University working on the dissertation topic “Perspectives of Girls, Families, and Healthcare Workers on Accessing Services for Adolescents with Perinatal HIV in Nigeria.” This means that I am interested in knowing how adolescent girls living with HIV can receive the services they need. What are their experience living with HIV, the drug they always take, and the experience of their parents/guardians and health workers who take care of them at home and in the health facility, respectively? I hope that the answers you provide to the questions I shall ask you will help doctors, nurses, other healthcare workers, parents, and family members best provide for and take care of adolescent girls living with HIV. This research should improve how adolescent girls living with HIV manage their treatments and medications and how best they can be helped overcome the challenges they face due to HIV so they can live long, healthy and achieve their life’s dreams. I appreciate your decision to participate in this study. I will be asking you some questions, and I anticipate this interview will take 60 minutes of your time. During the interview, I will be recording the session with an electronic recorder. All information gathered will remain confidential as your identity will not be made known to anyone nor be mentioned in the study. Do I have your permission to record the interview to ensure that I remember what you say? “YES/NO.” You do not have to answer any question that you do not want to. Please note that you may stop the interview at any time. You are free to leave the interview at any time without prior notice, and you will not be penalized. If you have questions, you can ask me.
Questions:	
1	Can you please describe how your daughter* got to know about her HIV status*? (Probe for disclosure by the caregiver or health care provider). If the caregiver/parent did HIV disclosure, ask the next question.* ** Refer to the girl depending on the relationship,*
2	For parents with PHIV adolescent girl: How difficult was it for you to disclose your daughter’s HIV status to her? *(Probe for his or her experience)*

3	For parents with BHIV adolescent girls: How difficult was it for you when you learned of your daughter's HIV status? Can you share your experience? (*Probe for how she got to know about the daughter's status*)
4	How do you feel about your daughter being infected perinatally with HIV?
5	Can you share your experience with us on how your adolescent girl cares for herself by taking her pills on time and eating well? (Probe for missing periods)
6	What are the difficulties you perceive that your daughter has in managing her illness? *(Probe for any unpleasant incident at the health facility, family, community, school, etc.)*
7	What specific difficulties do you have in caring for your daughter in ensuring she takes her medications?
8	How have you overcome these difficulties?
9	Do you receive any external support to care for your daughter? *(Probe for assistance from other family members, funded programs by government/international funded programs, health facility)*
10	Do you think that your daughter knows to ask for help when she needs it? *(Probe for transport support to visit the health facility/support group* meetings or personal needs; sanitary pad etc.)
11	Without any assistance, would your daughter be able to manage her treatment?
12	How do you help your daughter to take her ARV?
13	Do you find the treatment provided to your daughter by the health facility is helpful? Can you share your experience or what you think about the health facility services?
14	How do people in your community assess people living with HIV, especially adolescents? *(Probe for stigma and discrimination associated with HIV)*
15	If this is a problem, how do you address it, and how best can the community address it?
16	What type of support would you need to make life better for your daughter and your family?
17	From your experience, can you describe how the healthcare facility can improve HIV services for adolescent girls living with HIV to make them live longer and healthier?
18.	Is there anything else you would like to share with me before we end the interview?
Closing statement	Thank you for your patience and time.

Appendix C: Interview Protocol- Health Care Workers

Category	**Health care worker**
Introduction	I am Joseph Inyang, a Ph.D. student from Walden University working on the dissertation topic "Perspectives of Girls, Families, and Healthcare Workers on Accessing Services for Adolescents with Perinatal HIV in Nigeria." I hope that the answers you provide to the questions I shall ask you will help doctors, nurses, other healthcare workers, parents, and family members best provide for and take care of adolescent girls living with HIV. This research should improve how adolescent girls living with HIV manage their treatments and medications and how best they can be helped overcome the challenges they face due to HIV so they can live long, healthy and achieve their life's dreams. I appreciate your decision to participate in this study and ask you some questions, and I anticipate this interview will take 60 minutes of your time. During the interview, I will be recording the session with an electronic recorder. All information gathered will remain confidential as your identity will not be known to anyone or mentioned in the study. Do I have your permission to record the interview to help ensure the accuracy of the notes taken? "YES/NO." You do not have to answer any question that you do not want to. Please note that you may stop the interview at any time. You are free to leave the interview at any time without prior notice, and you will not be penalized. If you have questions, you can ask me.
Questions:	
1	Please describe your experience working with adolescent girls living with perinatal and behavioral HIV? Do you have different service delivery models for these groups of the adolescent population?
2	Are services provided free to adolescents living with HIV in your facility? (*Probe for user fees if services are not free and how adolescents pay for the services they receive*).
3	What are the common challenges to HIV status disclosure you have identified or experienced in 1. Caregivers and adolescents 2. Adolescents and health care workers *(Probe for adolescent choice; preference for caregivers or preference for HCWs and why?).*
4	Based on your experience, what are some of the health problems or opportunistic infections associated with these adolescents you noticed in your facility?

5	How often do adverse reactions to ARV occur among these adolescents, and how are they treated?
6	Do some of the adolescent girls with HIV you know in your facility have problems with adherence? What types of problems and why?
7	Can you please describe how you address adherence to ART among adolescents living with HIV?
8	What services are available to adolescent girls living with HIV in your facility?
9	What are the barriers or challenges that you face providing these services you mentioned to adolescent girls living with HIV? (Probe for drug stockout and how often this occurs, missed appointments, lost to follow up)
10	How were you able to overcome these challenges?
11	Have you or anyone of your colleagues experienced a time when an adolescent with HIV complained of being embarrassed by a staff? *(Probe for how many times this occurred).* If yes, please share your experience.
12	How was the problem resolved (*probe for staff capacity building on preventing stigma and discrimination associated with HIV*)?
13	After the problem, was confidence restored such that more adolescent girls with HIV now visit the health facility *(request to know/see daily attendance)*
14	Do you have support groups for adolescents living with HIV? If yes, can you provide more information about this? (*Probe for specifically for girls living with HIV*))? How often do they meet?
15	Are there noticeable improvements in the attitude of adolescent girls with HIV towards adherence to ART who attend the adolescent support group? (*Probe for viral suppression among these girls who have improved adherence to ART*)
16	Can you please describe your services on the transition from pediatric to adult care for eligible adolescents' girls living with HIV?
17	What are the common challenges associated with the transition for adolescent girls living with HIV to adult care you have noticed in your facility, and how did you overcome them?
18	How can services at your health facility be improved for adolescent girls living with perinatal/behavioral HIV?
19	Is there anything else you would like to share with me before we end the interview?
Closing statement	Thank you for your patience and time.