EXPERIENCES OF ADOLESCENTS LIVING WITH HIV
AT THE FEVERS UNIT, KORLE BU TEACHING HOSPITAL

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THIS THESIS/DISSERTATION IS SUBMITTED TO THE UNIVERSITY
OF GHANA, LEGON IN PARTIAL FULFILMENT OF THE
REQUIREMENT FOR THE AWARD OF MASTER OF PHILOSOPHY
NURSING DEGREE

JULY, 2017
DECLARATION

I, Gifty Mensah, do hereby declare that with the exception of the references used from other research and writers which have been duly acknowledged, this thesis is my original work which has been produced out of my research. This thesis has neither in whole nor part been presented to my institution or any other institution for the award of any degree.

Gifty Mensah
Student

This thesis has been presented for examination with our approval as supervisors.

Dr (Mrs) Patience Aniteye
Date

Dr Daniel Kojo Arhinful
Date
DEDICATION

I dedicate this work to the Almighty God for bringing me this far. I also dedicate this thesis to my parents Mr. Richard Kenneth Atiadze and Rose Atiadze, siblings and friends for their encouragement and support.
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<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Virus</td>
</tr>
<tr>
<td>ALHIV</td>
<td>Adolescent Living with Human Immuno-deficiency Virus</td>
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<td>ART</td>
<td>Anti-Retroviral Therapy</td>
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<td>BPS</td>
<td>Biopsychosocial</td>
</tr>
<tr>
<td>HAART</td>
<td>Highly Active Antiretroviral Therapy</td>
</tr>
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<td>HIV</td>
<td>Human Immuno-deficiency Virus</td>
</tr>
<tr>
<td>HPV</td>
<td>Human Papilloma Virus</td>
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<tr>
<td>JHS</td>
<td>Junior High School</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-Governmental Organisation</td>
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<td>NHIS</td>
<td>National Health Insurance Scheme</td>
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<td>OPD</td>
<td>Out Patients Department</td>
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<tr>
<td>PLWHA</td>
<td>Persons Living With HIV/AIDS</td>
</tr>
<tr>
<td>SHS</td>
<td>Senior High School</td>
</tr>
<tr>
<td>STIs</td>
<td>Sexually Transmitted Infections</td>
</tr>
<tr>
<td>SRH</td>
<td>Sexual and Reproductive Health</td>
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<tr>
<td>WHO</td>
<td>World Health Organisation</td>
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ABSTRACT

Living with Human immunodeficiency Virus (HIV) is challenging for any person especially during the period of adolescence. Many studies suggest that the services rendered in resource limited-countries do not meet the specific needs of adolescents living with HIV because little is known about their experiences. The purpose of this study was to explore the experiences of adolescents living with HIV and receiving treatment, care, and support at the Fevers Unit of the Korle Bu Teaching Hospital in Accra. A descriptive exploratory qualitative design was used in this study. Purposive sampling method was used to select adolescents between the ages of 14-19 years and an interview guide was used for data collection. Saturation was reached by the 12th participant. Data were analysed using thematic content analysis and eight main themes emerged from the data. These were disclosure of illness to family and significant others/reasons, Anti-Retroviral Therapy (ART), care at the hospital and secrecy. The other themes included sources of infection/ramifications, selected experiences of adolescents, coping/support and future prospects. The findings showed that although the diagnosis and disclosure of HIV to adolescents brought feelings of sadness, worry and depression, the adolescents were determined to follow the medical instructions and comply with the treatment to live long and to be in good health. The adolescents kept their diagnoses a secret from some family members and significant others and disclosed it to people they could trust. The adolescents expressed the positive effects of the ART on their health. However, the side effects and the strict treatment regime were challenging for them. Parental/family support and encouragement from health professionals helped the adolescents to cope with their conditions. In the absence of social support networks, these adolescents found strength in their religious beliefs which helped them to cope with their conditions.
Although the adolescents received information about their diagnoses and treatment, knowledge on sexual and reproductive health were inadequate. Despite all the difficulties they experienced, the adolescents were hopeful and positive about the future with education as a backbone to achieve career plans. There is a need for the provision of age-appropriate information on sexual and reproductive health for the adolescents to make informed decisions. Additionally, social support networks should be established for adolescents living with HIV as a platform to enable the adolescents share information and strengthen each other to be able to go through the adolescence phase.
CHAPTER ONE
INTRODUCTION

This chapter presents the background to the study of experiences of adolescents’ living with HIV, statement of the problem and objectives of the study. It also covers the purpose of the study, research questions, significance and, operational definition of terms used in the study.

1.1 Background of the Study

The Human Immunodeficiency Virus (HIV) is a virus from the Retroviridae family of Lenti viruses. When an individual is infected with the virus, it progresses and causes Acquired Immune Deficiency Syndrome (AIDS). The disease has been reported globally as well as in Africa. In Ghana, the first case of AIDS was reported in March 1986 (Ghana, 2008a) and has since been a national concern due to its high mortalities among infected persons. The first comprehensive report on AIDS in Ghana was documented in January 1991 in which 107 Human Immuno-deficiency Virus (HIV) cases were recorded in 1987. By the end of March 1988, three hundred and thirty three (333) persons were identified as HIV positive. In April 1990, out of two thousand seven hundred and forty four (2,744) people, 1,226 were stated to have been infected with AIDS (Ghana AIDS commission, 2008b).

Universally, young women between the ages of 15-24 years have HIV infection rates twice as high as in young men of the same age range (15-24) years) and this accounts for 22% of all new HIV infections and 31% of new HIV infections in Sub-Saharan Africa. The majority of adolescents living with HIV were born with the virus and some adolescents also acquired it during their adolescence (Global Report, 2013). In 2012, about 2.1 million
adolescents between 10 to 19 years were living globally with HIV and most of them were perinatally infected (Nöstlinger, Bakeera-Kitaka, Buyze, Loos, & Buvé 2015).

There is improvement in relation to a decline in HIV prevalence among young people (aged 15–24 years) in 21 of 24 countries in sub-Saharan Africa. The decline in HIV prevalence and falling new HIV infections among young people worldwide and especially in Sub-Saharan Africa, are happening concurrently with behavioural changes such as abstinence from sex, being faithful to one sexual partner and a rise in the use of condoms among young people with many sexual partners (Ghana AIDS Commission, 2015a).

World Health Organisation (WHO, 2010) defines adolescence as a developmental phase between 10 to 19 years; a phase of physiological, mental and emotional growth chiefly described by sexual growth, a rise in the involvement in risk taking behaviour and greater yearning for freedom (Sawyer, Drew, Yeo, & Britto, 2007).

Adolescence is also defined as persons between 10 and 19 years; it is a specific developmental stage between childhood and adulthood, characterised by physical, social and behavioural changes, including sexual growth, greater independence, and developing legal capability (Jaspan, Li, Johnson, & Bekker, 2009a).

In 2010, young people aged 15–24 accounted for 42% of new HIV infections in people aged 15 and older. Among young people living with HIV, nearly 80% (4 million) live in Sub-Saharan Africa. At the end of 2012, an approximated 2.3 million children were living with HIV infection globally; of whom 90% live in Sub-Saharan Africa (WHO, 2012). Currently, there are 1.6 billion people between the ages of 12-24 years living with HIV/ Acquired Immune Deficiency Syndrome (AIDS) in Sub-Saharan Africa, the largest generation of adolescents and young people ever (Ghana AIDS Commission, 2015b).
When the United Nations High-Level Meeting on AIDS was held in 2006, governments of the world pledged “to ensure an HIV-free future generation through the implementation of comprehensive, evidence based prevention strategies, responsible sexual behaviour, including the use of condoms, evidence and skills-based youth specific HIV education, mass media interventions, and the provision of youth friendly health services” (Piot, 2006).

Ghana, like any other country in Sub-Saharan Africa, has been affected by the Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (Ghana, 2008b). An estimated 150,000 people were infected with the virus as of 2014. The prevalence of HIV was at 1.37 in 2015 with the Greater Accra region leading with 3.2 percent (Commission & others, 2015b). An estimated 9,600 children less than 15 years are living with HIV/AIDS in Ghana. As of 2013, nearly 180,000 children under age 17 had lost one or both parents to AIDS (Visser, 2008).

Living with HIV deepens the need for effective support and guidance in going through this developmental phase, particularly as HIV-positive adolescents initiate sexual relationships, accept greater responsibility for adherence to treatment and get ready for adult life. Consequently, safer-sex, family planning and disclosure of HIV status gain prominence during adolescence (Braeken, Shand, & Silva, 2010).

Although the overall number of HIV-related deaths declined by 30% since the highest 8 years ago (WHO, 2014), estimates recommend that HIV deaths among adolescents are escalating. This upsurge, which has been mainly in the Africa Region which may reveal the fact that although more children with HIV survive into adolescence, they do not all get the care and support they require to stay in good health and prevent
transmission. In Sub-Saharan Africa, only 10% and 15% of young men and women (15 to 24 years) know about of their HIV status (Idele et al., 2014a).

In response to the epidemic, the Government of Ghana set up the Ghana AIDS Commission which organises and directs efforts among Non-Governmental Organisations (NGOs), international organisations and other groups to support the education and management of HIV/AIDS throughout Ghana and lessening AIDS issues in Ghana (Commission & others, 2012; Ghana, 2008b).

1.2 Statement of the problem

Globally, more than two million adolescents between the ages of 10 and 19 years are living with HIV, and many do not receive the care and support that they need to stay in good health and prevent transmission (Gore et al., 2011). Sub-Saharan Africa is home to over 1.7 million adolescents living with HIV (ALHIV) (WHO, 2013). Adolescents are becoming a more noticeable sub-group among those living with HIV as increased access to antiretroviral therapy (ART) allows growing numbers of those infected perinatally to reach adolescence while new adolescent infections remain high; in addition, it is now recognised that a higher proportion of perinatally infected children than originally believed are reaching adolescence without ART (Ferrand et al., 2009).

The World Health Organisation (WHO) has attributed the excess HIV-related mortality among adolescents to their low prioritisation in national HIV plans and the lack of accessible and acceptable testing and treatment services, including ART adherence support, for adolescents (WHO, 2013).

Adolescents living with HIV/AIDS experience numerous psychosocial stressors apart from the biological manifestation of the disease over a prolonged period of time which is burdensome to them. These could be related to the initial diagnosis and disclosure of their
HIV status, the emotional and financial burden of long term care and discrimination, bereavement related to the death of loved ones or fear about their own death and concerns about evolving sexuality and aspiration for relationships and families of their own (Jena, 2014a).

It is during this period that adolescents are really able to face the disease as a clinical phenomenon. (Fernet et al., 2007; Fielden et al., 2006). The disclosure and the new phase of adolescence, induces responses to illness, while they attempt to make sense of their disease and incorporate an HIV identity to their evolving adult selves (Kang, Dunbar, Laver, & Padian, 2008).

With this knowledge about their HIV diagnosis, adolescents face the cultural and societal definitions of HIV/AIDS, which is now part of them. This pushes the adolescents to embark on a quest to find out what HIV means to them in a society and culture where the definition of HIV/AIDS triggers stigmatisations (Deacon & Stepney, 2007a). Other adolescents may keep their distance from their peers who are HIV positive as a form of stigma (Campbell, Skovdal, Mupambireyi, & Gregson, 2010). These experiences make adolescents vulnerable to stigma as they are more likely to be blamed for their status which affects their self-worth and self-esteem. Adolescents living with HIV (ALHIV) face these challenges in the home, school or other social gathering (Jena, 2014).

While HIV-related deaths decreased globally by 30% from 2005 to 2012, those among adolescents living with HIV increased by 50%. This difference is mainly due to inability to deal with the peculiar needs of ALHIV and leading to poor clinical outcomes linked to late diagnosis and poor compliance to antiretroviral therapy. Moreover, many programmes have placed so much attention on strategies for primary prevention of HIV infection among adolescents and less focus on those who are already infected with the virus.
Adolescents Living With HIV

(Coates, Richter, & Caceres, 2008). Little attention has been given to the experiences of adolescents who are already infected (Winskell, Miller, Allen, & Obong’o, 2016).

The HIV epidemic continues to take a devastating toll on young people as increasing numbers of children who acquired HIV perinatally are now reaching adolescence due to the introduction of highly active antiretroviral therapy (Bundock et al., 2011; Foster & Fidler, 2010). Whether behaviourally or perinatally infected, adolescents require modern public health strategies that respond to their unique developmental and health needs that effectively absorb the adolescents in lifelong HIV care and treatment (Jaspan, Li, Johnson, & Bekker, 2009b).

The failure to support effective and acceptable HIV services for adolescents has resulted in a 50% increase in reported AIDS-related deaths in this group compared with the 30% decline seen in the general population from the year 2005 to 2012 (WHO, 2014). New World Health Organisation recommendations released in the run-up to World AIDS Day, 2013 are the first to address the specific needs of adolescents living with HIV/AIDS (HIV, 2013). Adolescents living with HIV require services that will be suited to meet the needs of their developmental stage so they can successfully go through this phase (Dowshen & D’Angelo, 2011). According to WHO as of 25th November, 2013, more than two million adolescents between the ages of 10-19 years were living with HIV globally and many do not receive the care and support that they need to stay in good health (UNAIDS, 2014).

The population of adolescents in Ghana is made up of about 12% and 11% respectively of the 10-14 years and 15-19 years in a total population of about 24.51 million people (Ghana Statistical Service, 2010). The population of adolescents living with HIV/AIDS is mostly made up of those who have carried the virus since birth who are
emerging as a progressively important and unique population whose experiences need to be known and understood as well as those who were infected in their adolescence (Jena, 2014b).

In response to the increasing records of adolescents living with HIV, the Fevers Unit of the Korle Bu Teaching Hospital started an adolescent and young adults’ clinic in June, 2012 to give focused, comprehensive HIV/AIDS care to adolescents and young adults. Although the unit has put structures in place to ensure that the adolescents receive optimal form of medical care, treatment and support, it is still ill-equipped in addressing specific needs appropriate for the developmental stage of these adolescents.

The clinic started with less than ten (10) adolescents living with HIV/AIDS. This number has increased significantly as the clinic had two hundred and three (203) adolescents as of 2016. Documented statistics on their clinic attendance commenced from the year 2014.

Additionally, apart from the limited statistics, not much research exists on the experiences of adolescents living with HIV in Ghana as indeed is also the case for adolescent-specific HIV-related data in Sub-Saharan Africa (Idele et al., 2014b). Hence the need for this study.

1.3 Purpose of the study
The purpose of this study was to explore the experiences of adolescents living with HIV at the Fevers Unit, Korle Bu Teaching Hospital.

1.4 Specific Objectives
This study sought to:

1. Explore the psychological effects of HIV on adolescents.
2. Explain the social issues affecting adolescents living with HIV.
3. Illuminate the effects of treatment of HIV on adolescents.
4. Describe the coping strategies of adolescents with HIV.

1.5 Research Questions

The questions developed to guide the research were as follows;

1. What are the psychological effects of HIV on adolescents?
2. What are the social issues affecting adolescents living with HIV?
3. What are the effects of treatment of HIV on adolescents?
4. What are the coping strategies of adolescents with HIV?

1.6 Significance of the Study

A study of this kind is significant in the field of Public Health and Social Sciences. The findings of this study will provide more information on management and treatment gaps, and the challenges faced by adolescents living with HIV. This will contribute towards the development of policies and programmes by the Ghana AIDS Commission, National AIDS Control Programme (NACP) in rendering services tailored to meet the peculiar needs of adolescents living with HIV/AIDS. Furthermore, the findings from this study will assist policy makers to identify the lapses in policies related to adolescents in order to ensure their implementation. The study will inform support groups and development partners to identify areas of training and support as well as provide financial assistance to these adolescents. Additionally, a study of this kind will provide information on what strategies to develop for adolescents to cope better with HIV. Therefore, future research could focus on developing intervention models for coping for adolescents living with HIV/AIDS.

1.7 Operational Definitions

Experiences: The process of doing and seeing and of having things happen to you.

Adolescents Living with HIV: Young persons between the ages of fourteen (14) to nineteen (19) years who have been diagnosed with HIV.
**Human Immunodeficiency Virus (HIV):** A retrovirus that causes AIDS and destroys the body’s ability to fight off infection and disease, which ultimately leads to AIDS (UNAIDS 2011).

The next chapter discusses the theoretical framework as well as the related literature of this study. The study draws on the biopsychosocial model (Engel, 1981). This model demonstrated an understanding of theories and concepts that were relevant to this study and related to the wider areas of knowledge being considered.
CHAPTER TWO

LITERATURE REVIEW

This chapter reviews the theoretical and empirical related literature on adolescents living with HIV. The literature was organised into four sections. The first section included a detailed discussion of the theoretical/conceptual framework; the biopsychosocial model. The second section reviewed the biological/treatment effects of HIV on adolescents. The third section discussed literature of the psychological effects of HIV on adolescents. The fourth section discusses the social effects of HIV on the adolescents and the coping strategies they use in dealing with the disease. Information was sourced from databases such as “EBSCOhost”, “Google scholar”, “Science direct”, “Popline”, “PubMed”, articles, reports from seminars and workshops as well as documents from health facilities such as the Korle Bu Teaching Hospital and Fevers Unit and reports from the Ghana AIDS Commission, World Health Organisation and UNICEF among others.

2.1 Theoretical/Conceptual Framework and Justification

A conceptual framework is a structure that can hold or support a theory underlying a particular study. It introduces and describes the theory that explains why the research problem being studied exists. The conceptual framework demonstrates an understanding of theories and concepts that are relevant to the study and relates to the broader areas of knowledge being considered.

Many conceptual frameworks and models have been used in HIV studies such as the Health Belief model, Disclosure model, Social-ecological model and others but this study chose the biopsychosocial model of illness to explain the different aspects of the experiences that adolescents go through as a result of living with HIV (Swendeman, Ingram & Rotheram-Borus, 2009). In other studies where the biopsychosocial model was used, it was shown that
psychological, behavioural and social factors interact with pathological processes in the development and course of physical disorders and these have substantial effects on compliant treatment (Swendeman, Ingram & Rotheram-Borus, 2009). Secondly, disease prognosis affects the psychological, social and medical well-being of people leading to depression, social isolation and immune dysfunction (Aijaz, Ansari, Siddique, and Dogar 2015). The biopsychosocial model was selected to inform this study because the constructs in the model and their inter-relationships were best suited to all the aspects of the illness experience of the adolescents. The objectives set for this study were also derived from the constructs of the BPS model thus they were appropriate and applicable to the variables that were considered in this study.

2.1.1 The Biopsychosocial Model

This model was first developed by an American Psychiatrist named George L. Engel in 1977 as a challenge to the medical profession to review a strictly biomedical approach to medical education and care. Engel contended that humans are biological, psychological, and social beings who act in certain ways that can either promote or destroy their health. This means that there are many different forces at work, from the cellular to the social, and each of these factors can contribute to health and illness. The consequence of this is that, a disturbance in any area of human functioning will affect all the areas (Novack et al., 2007). He intended to understand all of the facets that led to the development of certain medical conditions in order to provide a top level of care.

The biopsychosocial model understands health and illness through biological, psychological and social factors. The model states that all issues relating to health are results of a complex interaction of these three factors. In the layman's terms, the biopsychosocial model is known as the “mind-body connection”. In explaining the model, Engel emphasised
the distinct aspects of care: the patient, the patient's social context, and the means in place for dealing with illness, namely doctors and the larger system of health care (Engel, 1981a).

Biological influence plays a key role in the biopsychosocial (BPS) model. The biological component of the model refers to the fact that pathogens such as germs and toxins precipitate illness. In this aspect of the model, the physiological causes of an illness are identified and studied. The theories behind the BPS model, however, view biological factors as only one part of the illness and that no illness manifests itself based solely on physiological grounds. It must work in conjunction with other deciding features.

Psychological influence is a chief feature. Under this aspect of the model, a healthcare provider will look for underlying psychological issues that contributed to the development of the patient's condition. There are a variety of psychological influences that can contribute to an illness or a health problem, including depression, negative thought patterns and a lack of self-control.

The social influence aspect of the BPS model examines the illness from a sociological perspective. Engel deduced that considerations such as socio-economic status, religion, culture, poverty and technology can play pivotal roles in the development of the disease. Personal belief systems are also thought to be of significant importance in the development of illness. The model presumes that it is important to handle the patient's biological, psychological and social factors together when managing a health problem.
Figure 2.1: Theoretical Framework - BPS Model

Given the description of the model, the researcher explains it as follows:

**Biological**
- Pathology
- Symptoms
- Medication

**Psychological**
- Depression
- Stress
- Identity
- Guilt

**Social**
- Family
- Friends
- Hobbies
- Isolation
- Money


**Biological**: When an adolescent is infected with HIV, the virus attacks the immune system which is the defense system of the body. The body becomes prone to opportunistic infections which result in physical illness exhibited by signs and symptoms. Immunosuppression coupled with their developmental stage predisposes the adolescents easily to stress (Perreau, Levy, & Pantaleo, 2013). Subsequently, these adolescents who are put on Antiretroviral Therapy (ART) based on the outcome of their laboratory tests may experience side effects of
these medications which can be burdensome to them. Series of laboratory tests are done to monitor their progress on the ART (Sayles, Wong, Kinsler, Martins & Cunningham, 2009).

**Psychological:** Diagnosing an adolescent with HIV can be traumatic to them. Depression may result especially when the adolescents learn the disease is incurable and they have to live with it for the rest of their lives. This can lead to loss of self-esteem and self-worth. The adolescents may become apprehensive and anxious about dying which further stresses their condition (Jena, 2014). How the adolescent is able to cope with the news can affect his/her health positively or negatively. The personality, attitudes, and perceptions of the adolescents can affect their coping skills in dealing with the disease.

**Social:** The relationships the adolescent has with the family, peers/friends and school mates may have a positive impact in relation to coping with the disease which can have an effect on his/her psychological well being. The way the family and peers/friends accept and relate with the adolescent irrespective of the disease condition or diagnosis and their perceptions about the cause of the disease will determine how they relate with the adolescents. If they are rejected and shunned, they may isolate themselves and this could result in depression (Galano et al., 2017). However, if the adolescents are reassured and encouraged, they will positively look into the future with hope. This will be determined by how well informed and educated the family, peers/friends and school mates are on HIV/AIDS. If the family and significant others are unable to play their roles well, it would be difficult and challenging for the adolescent to go through this developmental stage with the disease (Ankrah et al., 2016).

### 2.2 Biological Effects of HIV on Adolescents

Naswa & Marfatia (2010) conducted a study in India to find out about the biological vulnerability of adolescents in terms of the anatomic and physiologic changes that occur in them as a result of HIV infection. The authors stated that, the immune system weakens,
grows slowly and becomes susceptible to repeated infections and illnesses in perinatally infected children. Subsequently, as children grow into adolescents, they are already physically underdeveloped and susceptible to numerous infections. Many HIV-infected children, particularly those with low resistance levels (Cluster of Differentiation count), do not build protective antibody response against vaccine preventable diseases such as measles after vaccination. Therefore, children remain vulnerable in their adolescence and later adulthood. The immune system of the adolescents offers a tough reaction to HIV, especially when adolescents are started on antiviral medicines, as compared with adults. Data from Paediatric AIDS Clinical Trials (381) revealed adolescents to have comparatively improved immune reconstitution after three (3) years of Highly Active Antiretroviral Therapy (HAART) than that of adults (Naswa & Marfatia, 2010). There was also a drift towards elevated viral loads in males, compared with females at similar CD4 counts. Additionally, increase rates of recurrence of Human Papilloma Virus (HPV) are prominent in female adolescents with HIV.

In a related five (5) year study of 983 HIV-infected children aged 6 to 18 years by Buchacz et al. (2003) in the United States of America, it was indicated that HIV-infected children may experience delayed puberty compared to HIV negative children. Thus, immunosuppression was connected with delayed pubertal onset in perinatally HIV-infected children. Besides, there is a lack of numerous micronutrients, especially vitamin A in these adolescents. Progressive stunting and ponderal growth appears to be the most common abnormality in perinatally infected children and adolescents and is accompanied by preferential decreases of fat-free or lean body mass. This stunting and growth retardation has an enormous psychological bearing on adolescents for whom the “body image” is one of the most significant issues in their lives.
Montessori, Press, Harris, Akagi and Montaner (2004) conducted a study to highlight the long term effect of antiretroviral treatment on adolescents. The study showed that long-term remission of the HIV-1 disease can be easily attained by combinations of antiretroviral agents. The suppression of plasma viral loads to less than the limit of quantification of the most sensitive commercially available assays (i.e., less than 50 copies/mL) and the coincident improvement in CD4 T cell counts is associated with resolution of established opportunistic infections and a decline in the risk of new opportunistic infections. However, continued treatment with combination regimens can be challenging to sustain because of problems with compliance to treatment and toxic effects. All antiretroviral drugs can have both short-term and long-term undesirable events. The risk of particular side effects differs from individual drugs, the class of drug, and from patient to patient (Montessori et al., 2004). The authors suggested that better understanding of the undesirable effects of antiretroviral agents is of concern to health care professionals who care for HIV-positive patients as they try to enhance therapy.

2.3 Psychological Effects of HIV on Adolescents

A qualitative study was conducted by Jena (2014) which explored the lived experiences of adolescents living with vertically acquired HIV receiving treatment, care, and support services in a Wellness clinic, in Port Elizabeth, South Africa. Six (6) adolescents with vertically acquired HIV infection between the ages of 16-17 years participated in the study. The adolescents that participated spoke about their illness and their past and present lives. The participants portrayed fear, worry, pain, and grief in their lived experiences. The adolescents were apprehensive about their own death and had experienced illness and death of family members and close relatives due to HIV and AIDS. The participants had pleasant experiences of HIV care at the clinic. The findings indicated that adolescents living with
Adolescents Living With HIV

Vertically acquired HIV encountered a lot of difficulties such as painful and distressing life occurrences connected to their illness which involved severe health problems and hospitalisations. These difficulties make it challenging for the adolescents to deal with their illness and its management. Secondly, taking Anti-Retroviral (ARV) was challenging to the participants due to side effects. The author recommended that intensive care services are needed to boost optimism and aid self-disclosure in adolescents living with HIV.

The research design used fits the study and the exploratory design used was suitable. The target population, as well as the sample, was clearly and correctly defined. Purposive sampling technique was used however, the sample size of six (6) appeared to be inadequate for an in-depth study. The study focused on adolescents between the ages of 16-17 years hence could not capture the experiences of other adolescents who were less than 16 years and above 17 years. Ethical issues in the methodology were dealt with. Interviews were conducted for the data collection and the interview guide covered the questions that were supposed to be asked. The purpose of the study was clearly stated. However, the study does not clearly state its objectives. The terms used in the study were clear. The presentation of the findings was clear and straight to the point. The discussions were related to the findings and the conclusions were also based on the findings.

Mburu et al. (2014) conducted a study among adolescents aged 10–19 living with HIV in Zambia with their parents and health care providers. According to the researchers, as adolescents living with HIV gain autonomy over their self-care and begin to engage in sexual relationships, their experiences of being told about their HIV status and of informing others about their HIV status may influence the way they cope with the disease. The authors concluded that adolescents who have been informed of their HIV status should be given constant and progressive support to stop disclosure from adversely affecting their
psychological and sexual well-being. The authors recommended that future research is required to explore the probable responsibility of family members who are trustworthy to help with the disclosure process.

Three different groups who were instrumental in caring for the adolescents participated but the study focused more on the adolescents. Not much was said about the parents and the health care providers.

Mutumba et al. (2016) conducted a study on the psychological distress among Ugandan Adolescents Living with HIV (ALHIV). The aim was to show how HIV infection escalates the risk of psychological distress among adolescents living with HIV (ALHIV), which also brings about a surge in risky behaviors such as non-adherence to medication, substance abuse, and sexual risk-taking. Therefore, the authors utilised the stress and coping framework to explore the risk and protective factors for psychological distress in a cross-sectional sample of 464 ALHIV (aged 12–19; 53% female) at a large HIV treatment centre in Kampala, Uganda. The findings showed that the stressors associated with psychological distress included daily hassles, major negative life events, HIV-related quality of life, and stigma. Protective factors included psychosocial resources such as religious coping, satisfaction with social support, and general coping style and behaviours. Social support and optimism were significantly associated with psychological distress. The findings highlighted the need for mental health services for ALHIV in Uganda and other resource-limited settings.

The sample size and the sampling method used for this study were adequate and appropriate respectively. The research design and conceptual framework used fits the study.

Similarly, an article was reviewed by Leserman (2008) to examine whether depression and stress may have an influence on immune and disease-related parameters in HIV disease. The interest was whether depression and stress may clarify the wide variability
in the disease course of patients infected with human immunodeficiency virus (HIV). The author reviewed what was known about the underlying biological mechanisms of HIV disease, such as adjustments in glucocorticoids and catecholamines, which may help elucidate these psycho-immune relationships. The review of the literature found extensive evidence that chronic depression and stressful events may affect HIV disease progression. However, little is known regarding the biological mechanisms that may account for these relationships. He concluded that more research is necessary to investigate how depression and stress might influence HIV disease progression and the type of interventions that might lessen the negative impact of chronic depression and trauma (Leserman, Ironson, O’cleirigh, Fordiani, & Balbin, 2008).

Kenu et al. (2014) conducted a baseline study in an HIV clinic in Accra, Ghana to ascertain the knowledge and disclosure of HIV among adolescents and young adults. Data collection was done using self-administered questionnaires on general knowledge on HIV, HIV treatment and disclosure. Thirty four (34) adolescents and young adults participated and the mean age was 16.9, SD 2.9 and 62 % (21/32) were female. The results showed that eighty five (85%) of the participants were aware that young people their age could fall sick. Ninety one (91%) had heard of HIV, 70% knew someone with HIV and 45% thought that adolescents were not at risk of HIV. On modes of HIV transmission, 66.7% knew HIV was sexually transmitted and 63.6% knew about mother to child transmission. Fifty three percent (18/34) knew their HIV status, 50% (17/34) were on Antiretrovirals (ARVs) and 35% (6/17) admitted missing ARV doses. Out of two participants who were on ARVS, one said he was HIV negative and the other did not know his HIV status. The researchers concluded that disclosure of HIV to adolescents and young adults depends on a combination of complex factors and most practitioners’ state an age that is developmentally appropriate for disclosure.
Thus disclosure is highly individualised. The knowledge and awareness of HIV was 91% among the participants compared to 97% in adults in the Ghana Demographic Health Survey however, only about two thirds had acceptable in-depth knowledge on HIV. Half of the participants knew their HIV status which was not good considering their ages. The authors recommended that there is the need to strengthen education to young persons with HIV, support adherence to ARVs for better outcomes and assist caregivers to disclose HIV status to the adolescents.

2.4 Social effects of HIV on adolescents

With respect to the qualitative study conducted by Mburu et al. (2014), adolescents aged 10–19 living with HIV in Zambia, their parents, and health care providers were interviewed with the aim of exploring the disclosure of HIV status to adolescents, adolescents’ disclosing their status to others and the influence these forms of disclosure on the adolescents. Through interviews and focus group discussions, the authors noted three main obstacles to disclosure of HIV status: local norms that prevent parents from interacting with their children on sexuality; fear of HIV stigma and the belief that adolescents would not understand the outcomes of HIV diagnosis on their lives and relationships. With regard to adolescents’ disclosing their HIV status to their sexual partners, the study recognised fear of rejection as a common obstacle. In some cases, family discussing about HIV openly helped adolescents to relate with an HIV diagnosis. The findings showed that disclosure had several outcomes at the individual and interpersonal levels. At the individual level, some adolescents expressed being anxious, depressed and blaming themselves after being told about their HIV diagnosis. At the interpersonal level, disclosure created opportunities for adolescents to have access to adherence support and other forms of psychosocial support from family members and peers. At the same time, it sometimes strained adolescents’ sexual relationships, although
it did not always lead to rejection. The authors concluded that, there is a need for public health interventions that guide adolescents living with HIV, their parents, and families through the disclosure process. Such interventions should help parents to weigh and appreciate the developing cognitive ability and maturity of their adolescents in order to decide the suitable time to disclose their HIV-positive status. The interventions should lessen the risk of HIV stigma, and local norms that may inhibit conversations of sexuality within families.

The study looked at different issues relating to the disclosure of HIV to adolescents which appeared to be a little complex. These could have been dealt with in separate researches to focus on either the adolescents or the caregivers for the findings to come out clearly. The recommendation of a disclosure process to guide parents to determine the appropriate time to disclose HIV status to adolescents by the authors was well spelt out.

Living with a prolonged illness is challenging at any phase of life, specifically when considering HIV/AIDS, a stigmatised condition that stimulates so much discrimination and may become an exacerbating factor when it occurs during adolescence. For this reason, Kourrousksi & Lima (2009) aimed to explore the experiences of adolescents with HIV/AIDS regarding medication adherence in São Paulo, Brazil. A descriptive study with a qualitative approach was conducted in which nine (9) adolescents between the ages of 12 and 18 years and six (6) caregivers participated. The data concentrated on the helpful and adverse aspects related to adherence. The findings revealed that adolescents have challenges adhering to medication especially due to their undesirable effects; adolescents try to normalise so that stigma and discrimination do not compromise their quality of life and treatment adherence. The authors recommended that adolescents need to be encouraged to adhere to treatment.
The method used fits the study, the stated objectives were clear and the target population was clearly defined. The sample size was however, inadequate for the study.

Abadía-Barrero and Castro (2006) carried out a related study in São Paulo, Brazil. The purpose was to describe and conceptualise the experiences of stigma in a group of participants living with HIV and estimate the outcome of access to Highly Active Antiretroviral Therapy (HAART) over the social course of AIDS and over the children's experiences of stigma. Through ethnographic research in São Paulo from 1999 to 2001 by Abadía-Barrero and Castro (2006), the life courses of 50 children aged 1–15 living with or affected by HIV were studied. Data collection was done through participant observation and semi-structured informal interviews and analysed using social theories on illness experience and social inequality. The findings demonstrated that stigma related to AIDS happens within complicated discrimination processes that change as children reach adolescence. The findings revealed structural violence in the forms of poverty, racism, and inequalities in social status, gender, and age stimulates children's experiences of stigma. The authors also described how access to HAART modifies the lived experience of children, reduces stigma, and brings new challenges in AIDS care such as adolescents’ sexuality and treatment adherence. The authors suggested that interventions to lessen the stigma that exclusively target the perception and attitudes of people living with HIV are restricted. In distinction, universal access to HAART in Brazil is a powerful intervention that reduces stigma, in that it alters AIDS from a devastating and incurable disease to a protracted and manageable one.

With respect to the qualitative study conducted by Jena (2014) where the author explored the lived experiences of adolescents living with vertically acquired HIV in a Wellness clinic, in Port Elizabeth, South Africa, the findings indicated that adolescents got to know about their HIV status in early adolescence and chose not to tell people outside the family due to
fear of rejection, stigma, and discrimination. Their school attendance and performance was affected by their illness. The family was an important resource of support for the participants. The author concluded that the adolescents need support services that will decrease and discourage stigma and discrimination at school and within their communities.

Hodgson, Ross, Haamujompa, and Gitau-Mburu (2012) conducted a study to explore and document the informational, psychosocial, sexual and reproductive health (SRH) needs of adolescents (aged 10–19 years) living with HIV and recognise the gaps between these needs and existing services in Zambia. Semi-structured interviews and focus group discussions were done with 52 HIV-positive adolescents and 59 key informants, including health care workers and parents/guardians. Participants were purposively selected from three sites; Lusaka, Kitwe, and Kalomo to ensure a broad representation of service-delivery settings in Zambia. Data were analysed inductively to extract key themes with the aid of NVIVO version seven (7) software. The findings confirmed that social networks have an important bearing on treatment adherence and help adolescents in coming to terms with an HIV diagnosis. The trauma of diagnosis, however, is aggravated if poorly handled. Nevertheless, many adolescents are resolute not to let HIV alter their lives. Adolescents want information on SRH and HIV, but service providers do not sufficiently meet these informational needs. Where available, tailored and participatory measures around HIV and SRH are significantly valued. Services that are welcoming, empowering and provide appropriate information are extremely cherished. The researchers recommended that adolescents living with HIV need effective, directed and sustainable HIV services to carefully go through adolescence.
The research design used was suitable and the sample size was adequate. The study involved the key players in the lives of the adolescents. The combination of interviews and focus group discussions for data collection was good.

Furthermore, a similar study was repeated two years later as the number of adolescents living with HIV in Zambia kept increasing, yet there was little knowledge about their experiences in a social context which could facilitate HIV programmes to respond better to their needs. Therefore, a qualitative study was conducted by Mburu et al. (2014) to examine the experiences of adolescents living with HIV in Kitwe, Kalomo, and Lusaka in Zambia. Interviews were conducted with a sample size of 58 adolescents aged 10–19 years living with HIV and their health care providers (14). Thirteen (13) focus group discussions were conducted with adolescents living with HIV (53), health care providers (24) and parents (21). Thematic analysis was used to illuminate the social–ecological determinants of adolescents' experiences. The findings showed that a range of factors located at the individual, family and peer, community and structural levels determine the experiences of adolescents living with HIV. At the individual level, resilience and internalised stigma influenced the adolescents' perception of an HIV diagnosis, and their capacity to uphold a positive outlook and maintain relationships. Family and peers supported adolescents to adapt to new medication routines, but the family and peers sometimes disclosed adolescents' HIV status incorrectly. At the community level, stigma and discrimination in schools were found to negatively influence adolescents' experiences, suggesting that approaches to normalise HIV in schools are needed. The presence of non-governmental organisations provided an entry point for the provision of broad-based livelihood, nutritional and psychosocial services for adolescents living with HIV at the community level. At the structural level, poor flexibility of clinic opening hours, staff shortages and a lack of health policies related to adolescents living with HIV presented
ongoing limitations to adolescents' ability to access relevant services. The authors concluded that, adolescents' experiences of living with HIV are influenced by factors located within and beyond adolescents themselves. Understanding these contextual factors, and adopting interventions that accentuate positive experiences while mitigating negative ones, could strengthen the provision of appropriate services that meet the needs and circumstances of adolescents living with HIV.

The sample size of fifty eight (58) adolescents was adequate and the study presented clear findings from the perspectives of the adolescents, health care providers and parents. Definition of terms used was clear as well as the findings.

According to Brown and Lourie (2000), more than one million children are infected with human immunodeficiency virus (HIV) worldwide and in the United States of America, which became the sixth leading cause of death among 15–24-year-olds. Despite the trend of increasing rates of infection, advances in therapies have led to survival for more than 65% of infected children. This global health threat continued to have a significant impact on child and adolescent psychiatry and psychology. The researchers reviewed current studies and report on the outcomes of the acquired immunodeficiency syndrome (AIDS) epidemic in the psychiatric care and development of children and adolescents infected with HIV. The review by Brown and Lourie (2000) also addressed HIV infection and its psychological and social implications. Several topics of mental health significance were examined: the epidemiology of HIV, neurocognitive development among those infected, psychological impact of infection, and, the family and social context of HIV. The transition of HIV from an acute, deadly disease to a sub-acute, chronic disease has huge implications for the neurocognitive and psychosocial development of children and families. As children and adolescents infected with HIV continue to live longer, normal developmental milestones and educational needs
will take on new significance. Many children will continue to be adversely impacted by non-
HIV factors such as poverty, scarce medical services, and a lack of social support. This 
analysis outlined latest developments that hold potential to effectively reduce the treatment 
burden on the infected, their families, and health care providers and to reduce the incidence 
of transmission to the uninfected (Brown & Lourie, 2000).

Abubakar et al. (2016) conducted a study to explore the psychosocial challenges HIV 
infected adolescents face on the Kenyan coast. They maintained that the rise in the uptake of 
antiretroviral therapy (ART) has led to an upsurge in the survival of vertically acquired HIV 
infected children, many of whom are growing into adolescence and early adulthood. A total 
of 44 participants including HIV-infected adolescents, HIV uninfected adolescents, and key 
informants. It was a qualitative study where individually administered in-depth interviews 
were conducted. The data was analysed using NVIVO version seven (7) software. The 
researchers noted that adolescents in rural Kenya faced challenges that could be categorised 
into six major themes: poverty, poor mental and physical health, the lack of a school system 
that responds to their needs, challenges on how to disclose to peers and family members, high 
levels of stigma in its different forms, and challenges of medical adherence leading to the 
need for close supervision. The authors concluded that in the African community, vertically 
amquired HIV-infected adolescents face a multifaceted set of social, economic and medical 
challenges. The authors recommended a crucial need to create multi-sectoral intervention 
support programmes to completely address these challenges.

A qualitative study was conducted by Ayres et al. (2006) in São Paulo, Brazil in a 
group of young people who acquired HIV infection perinatally. The aim was to explore the 
connotations ascribed by young people about “living as an adolescent with HIV” and the 
components entailed in the adherence to antiretroviral treatment. Twenty (20) participants
between the ages of 13-20 years were monitored at services specialised in the treatment of Paediatric AIDS. Semi-structured interviews were conducted on their individual histories, experiences, and challenges they must encounter while living with HIV/AIDS. The findings revealed central issues of being ‘‘normal’’ and ‘‘different’’ as expressed by the participants. However, living a normal life is assured by being responsible with one’s health, ensuring that the illness is kept secret and issues about HIV transmission and disclosure to a sexual partner.

In terms of treatment, the findings showed that adherence is an active process and involves instances of greater or lesser interest relating to caring for one’s health. The adolescents have ideas and visions and although HIV is regarded as a stressor, optimistic perceptions about the future existed. The authors concluded that, to live as an adolescent with HIV encompasses delicate components that need to be recognised and legitimised by professionals who monitor the course of these young people. Additionally, it is essential to permit a space in which the adolescents can reflect and find support concerning issues connected to the construction of their sexuality and care of one’s own body.

In Switzerland, Michaud et al. (2009) conducted a study with the purpose of finding out how Human immunodeficiency virus (HIV) positive adolescents deal with the challenges relating to their disease, treatment, and developmental tasks. This was a qualitative study that described some reasons why, and the degree to which, adolescents may or may not disclose their HIV status to others. A semi-structured interview was conducted with each of 29 adolescents who were 12-20 years old, twenty two (22) female and seven (7) males. The analysis of the content of the interviews identified relevant themes (e.g., disclosure), which were explored in detail. From the findings, out of twenty nine (29) participants, eight had not disclosed their condition to anyone outside the family, nineteen (19) had disclosed it to good friends, and sixteen (16) had disclosed it to some teachers. Four (4) participants had engaged
in public disclosure, and six (6) of ten (10) sexually active teenagers disclosed their status to their partners. The attitudes toward disclosure among younger adolescents were mostly related to those of the parents, particularly the mother. Older adolescents, occupied in their search for autonomy, tended to decide self-reliantly on what to say and to whom. Although adoptive parents would often encourage disclosure, biological parents, especially HIV-positive mothers, insisted on not disclosing the adolescent’s status for fear of stigma. The authors concluded that the health care team should methodically tackle the issue of disclosure with the adolescent and his or her family (adoptive parents), the purpose being to balance the right of the adolescent and that of the adolescent’s family to maintain privacy against the concerns of sexual partners, as well as the adolescent’s interest in revealing HIV status to relatives, school staff, and friends.

Furthermore, a qualitative study conducted in São Paulo, Brazil by Galano et al. (2017) to explore the experiences of the first generation of adolescents who acquired HIV through vertical transmission when disclosing their diagnosis to friends and romantic partners. Convenience sampling was used to select 20 patients (13-20 years old). Individual interviews were used with a duration of 45 minutes. The participants were followed in specialised clinics for the treatment of paediatric AIDS. The findings suggested that families who live with HIV tend to keep it a secret, and such behaviour is learned and accepted readily as natural. Respect for privacy and the fear of rejection, coupled with the belief that information about their disease will be spread, are the main beliefs with which participants rationalise their secrecy. In terms of romantic relationships, adolescents were aware that their HIV status should at some point be shared with current or future sexual partners. However, the decision to reveal an HIV diagnosis in romantic relationships is invaded by anxieties, uncertainties about the right time, and fear of abandonment.
However, telling the truth requires trust, guarantees of the other’s love, and, in some cases, questioning romantic partners beforehand to learn their perceptions about the disease. Participants who had experiences disclosing their HIV status shared positive and negative results, including emotional support, acceptance, and understanding, along with ostracism, discrimination, and abandonment by family members. The authors concluded that the findings of the study emphasise the challenges of revealing an HIV diagnosis to third parties. The authors recommended that understanding the meaning and importance of the secret for each patient, along with the conflict between the right to confidentiality and the responsibility of treating others exposed to the disease are aspects that should be deliberated comprehensively with adolescents living with HIV and incorporated into clinical practice. Religious beliefs and support from religious associations help the adolescents to believe that they belong to a larger force which makes them cope with the disease condition (Bernstein, D’Angelo, & Lyon, 2013).

2.5 Summary of Literature Review

From the literature review, it is quite evident from studies done elsewhere especially in Sub-Saharan Africa that adolescents living with HIV experience a lot of psychological and social stressors aside the biological or physiological effects as a result of the illness. Besides, these adolescents face numerous challenges with regards to medication adherence as well as coping with the disease. Countries such as Kenya, Brazil, India, Zambia, Uganda and South Africa have substantial data on adolescents living with HIV. However, there exists little published research in Ghana on the experiences of adolescents living with HIV in order to render age appropriate health care services to them. This has resulted in an extensive gap hence the decision to conduct this study.
The next chapter will address the description of the methodology used in the study in detail.
CHAPTER THREE

METHODOLOGY

This chapter presents the processes used to obtain the data and analysed. It includes the research design, research setting, target population, sample size and technique, and procedure. It also involved data gathering tool, data analysis, rigour and ethical considerations.

3.1 Research Design

The research design is the whole strategy that is employed to incorporate the different sections of a study in a comprehensible and reasonable way, thereby, ensuring the research problem is successfully addressed. It constitutes the plan for the collection, measurement, and analysis of data (Trochim, 2006). The study employed a descriptive exploratory qualitative design. The focus of qualitative research is to get an in-depth knowledge of the topic under study or understand the experiences of people and not to generalise (Holloway & Wheeler, 2013). This qualitative approach was deemed more suitable for this research because the experiences of adolescents living with HIV is an area not well researched into and qualitative inquiries are best suited for studies where little is known about the phenomena being investigated. The qualitative approach would yield thick descriptions of the area being studied. The research approach also enabled the researcher to gain a deeper understanding and described the experiences of the participants.

3.2 Research Setting

This study was conducted at the Fevers Unit, Out Patients’ Department (OPD) of the Korle Bu Teaching Hospital (KBTH) in Accra. The hospital is located in the Ablekuma South Sub-Metro District, Greater Accra region about 0.5km from the Korle-Lagoon.
Currently, the hospital operates as an autonomous body but under the Ministry of Health and the Teaching Hospital Act (Act 525). It is the premier and leading National referral centre in Ghana. It has one of the best facilities that train health professionals in the country such as; Nursing and Midwifery Training College, Public Health Nursing School, School of Peri-operative and Critical Care Nursing and Ophthalmic Nursing School. It also hosts the School of Allied Health Sciences, School of Medical Laboratory Technology, University of Ghana School of Medicine and Dentistry, and School of Radiologic Technology (Korle Bu Teaching Hospital, 2016).

The hospital has expanded with a bed capacity of 2000 and a staff strength of 3500, comprising doctors and dentists, nurses, pharmacists, a number of health service administrators, laboratory technicians and technologists, biostatisticians and other categories of staff. The hospital has eighteen (18) clinical departments and centres as at January 2017. These include the Obstetrics and Gynaecology, Surgery, Child Health, Polyclinic, Oral Maxillofacial Surgery, Medicine, Radiology, Pharmacy, Radiotherapy and Ear, Nose and Throat (ENT). Others are Haematology, Microbiology, Eye Clinic, Reconstructive Plastic Surgery and Burns Centre, Cardiothoracic Unit (CTU), Chemical Pathology, Clinical Psychology Department and the Mortuary. The corporate mission of the hospital is to provide quality tertiary health care, teaching, research, and outreach services (KBTH, 2016).

The Fevers Unit of the KBTH is an infectious disease unit that offers specialised care to Persons Living with HIV/AIDS and serves as the national referral centre for HIV infected patients. It has a total bed capacity of twenty seven (27) for in-patients and an Out Patient’ Department (OPD). The unit also has a mini laboratory, record and research units. The total population of HIV patients registered at the unit at the time of the study was over 23,000 with an adolescent and young adults’ population of 203. The staff strength of the unit was seventy two (72) which was made up of different categories of health workers. The HIV care
programme for the adolescents was established in 2012 to provide comprehensive HIV/AIDS care and management for clients/patients (Fevers Unit Annual Report, 2016). The adolescents and young adults’ clinic is held on Thursdays (patients/clients between the ages of 14-24 years) and the remaining working days are for adults.

The researcher chose this setting to recruit participants for the study because of accessibility and availability of adolescents living with HIV attending the clinic.

3.3 Target Population

The target population is the entire aggregate of participants in whom the researcher is interested (Polit, Beck, & Hungler, 2001). The target population for this study included adolescents between the ages of 14-19 years whose HIV status had been disclosed to them, on ART and attending the clinic at the Fevers Unit.

3.3.1 Inclusion Criteria

Adolescents between the ages of 14 -19 years who were aware of their HIV status as well as on antiretroviral therapy and spoke English or “Akan” (Ghanaian local dialect) fluently because the researcher was fluent in those languages. The adolescents were also willing and participated voluntarily in this study by signing the child assent form (Appendix I). For participants below 18 years, parental consent form were signed (Appendix H). Adolescents who were 18 years and above signed the consent form (Appendix G).

3.3.2 Exclusion Criteria

The study excluded adolescents below the ages of 14 years who could not speak English or “Akan” (Ghanaian local dialect), those who were too ill to be interviewed and adolescents who did not agree to take part in the study.
3.4 Sample Size and Sampling Technique

A sample refers to the tangible group included in a study from which data is collected and is drawn from the target population (Punch, 2013). In most qualitative studies, the final size of the sample can be determined during data collection when saturation is reached; that is a situation where no new information is being generated from the participants (Baker, Edwards, & Doidge, 2012; Walker, 2012). A letter was obtained from the School of Nursing and Midwifery, University of Ghana to seek for permission from the management of the hospital and the Head of the Fevers Unit. After permission was gained, the researcher informed the nurses at the OPD who assisted in recruiting the participants for the study. Adolescents who consented were interviewed at the clinic. Relevant data was collected till no further question was needed to be asked. Twelve (12) adolescents participated and were interviewed in this study. Saturation was achieved at the tenth participant; this is the point at which no new information was generated from the participants. However, two more participants were interviewed which confirmed the saturation.

Purposive sampling method was used to select participants for this study. This was non-probability sampling method which entailed selecting participants with the most characteristic or typical attributes of the population that serve the purpose of the study best (Grinnell Jr & Unrau, 2010). The purposive sample enabled the researcher to “hand pick” or selectively choose participants who were experiencing the phenomenon being studied and therefore have adequate knowledge about it.

3.5 Data Collection Tool

An interview guide (Appendix B) was used to conduct face-to-face individual interviews which explored the experiences of adolescents after being diagnosed with HIV. This tool was more appropriate for this study because it gave the participants the opportunity to express their views freely about the phenomenon under study. It also allowed the
researcher to ask probing questions for clarification. The interview guide was divided into two sections. Section A consisted of demographic data of the participants and the section B consisted of semi-structured open ended questions as well as probing questions (Appendix B). For instance, participants were asked questions such as “Tell me about your experience as a Person Living with HIV/AIDS (PLWHA) on antiretroviral therapy (ART).” The interview guide is presented as Appendix B.

3.6 Data Gathering Procedure

This was where the researcher used a step by step approach to gather the information. With the ethics approval letter, the researcher introduced herself to the Head of the Fevers Unit, the adolescents and young adults’ clinic in-charge through the Deputy Director of Nursing services. The adolescents and young adults’ clinic in-charge read through the ethical approval letter and introduced the researcher to the adolescents at the clinic.

The researcher established rapport with the adolescents and explained the whole study, its importance, and implications to the participants using the participant information sheets. A trained nurse and a counsellor who work at the unit assisted the researcher to select the participants. The date and time for the interview were chosen by the participants. The venue for the interview, which was one of the counselling rooms at the clinic was determined by the participants. According to the participants, this venue offered privacy and convenience which allowed them to be free to express themselves. On the day of the interview, the participants were presented with the Consent form (Appendix G) which they read, their questions were answered and clarified. The participants were made to sign the form before the interview began. For participants who were below eighteen (18) years, their parents/guardians were asked to voluntarily sign the Parental/Guardian Consent (Appendix H) and then the participants also signed the Child Assent form (Appendix I) before the
interview. Permission was sought from the participants and their parents/ guardians for the interview to be audio recorded.

The interviews were conducted in the English language and each interview lasted for forty five (45) to sixty five (65) minutes for each participant. The conversation focused on the disclosure of HIV to the adolescent, the disease experience, treatment effects, coping strategies and the support that the adolescents with HIV receive. Generally, the interview started with less sensitive questions and then followed by sensitive ones. An audio recorder was used to record the interviews and non-verbal cues of participants such as facial expressions, mannerisms, and gestures were documented as field notes. Probing questions were asked where answers provided by the participants were not clear to the researcher. Additionally, a field note which contained information on the mannerisms, interruptions during data collection process, environment, biases of the researcher’s thoughts and feelings were kept. Due to the sensitive nature of the interview, the services of a trained Counsellor was provided in case of any emotional distress to the participants but none made use of her services (Appendix F). However, the researcher referred the participants to the trained Counsellor after each interview to assess their emotional states.

The researcher thanked and appreciated each participant at the end of the interview session and provided them with snack and transportation. The participants were informed that the researcher may seek further clarification if needed.

3.7 Pilot Study

(Graham et al., 2003) have stated that a pilot study is used to fine-tune the main study and throw up unexpected difficulties the researcher could face in the actual study and the difficulties that the researcher can tackle before the actual study.
A pilot study was conducted after the approval of the research proposal prior to the actual collection of data. The data collection tool (Appendix B) was piloted at the Princess Marie Louis Hospital in Accra. This hospital was chosen for the pilot study because it runs an HIV clinic for adolescents similar to that of the main study setting. The semi-structured questions were used to interview two (2) adolescents who met the inclusion criteria. Data analysis of their responses were used to effect changes in the interview guide before being administered to the main participants. It also helped to improve the interviewing skills of the researcher.

### 3.8 Data Analysis

Data analysis is the systematic organisation and synthesis of the research data and the testing of research hypothesis using those data (Polit & Beck, 2010). Data collection and analysis were done concurrently. The data were analysed using thematic content analysis based on the constructs of the biopsychosocial model of illness. The process involved in data reduction, data display, and drawing conclusion and verification were used (Miles, Huberman, & Saldana, 2013). The audio recordings were listened to by the researcher and then transcribed verbatim. This enabled the researcher to familiarise herself with the data.

The field notes (recorded observations of participants) were read and added to the data on the same day the interview was conducted. The transcribed data was compared script by script across all the interviews. The transcribed data was read several times in order to get insight and in-depth meaning and to identify patterns in the data. As the researcher continued to read the transcribed data, certain patterns identified within the data such as similar ideas, thoughts and words were noted as codes.

Phrases or persistent words were coded by writing them in the margins of the transcribed data. Codes that were related were grouped together into themes and sub-themes. A thematic code frame was developed to categorise all the sub-themes to ensure that the data
fits into the various categories. The categories that were identified were coded with subheadings and saved in a file. Each new category that was identified was pasted in the file. This was done progressively for all the transcripts. During the analysis, exact words and quotes were reported verbatim as expressed by the participants. Conclusions were drawn from the themes and categories identified to present the experiences of adolescents living with HIV. A number of discussions were held with the supervisors and this ensured that the findings represent the responses of the participants.

3.9 Data Management

The data collected during the research was stored and secured on a computer with a password to uphold the confidentiality of the participants. The demographic data and the consent forms were separated from the main interview which ensured that linkages between them were not made. The interview materials (audio recordings, transcripts, and field notes) were kept in a cabinet under lock and key in the custody of the researcher which could only be accessible to the researcher and her supervisors by the use of a password. The transcribed data has been stored on an external hard drive to prevent data loss. All other documents relating to this study and the data would be kept and discarded after five years according to the tenets of the University of Ghana.

3.10 Rigour/Trustworthiness

The terms used to describe rigorous qualitative research or promote trustworthiness of qualitative research include credibility, dependability, confirmability, and transferability (Guba, 1981; Krefting, 1991).

Credibility was ensured by establishing a true presentation of the phenomenon being studied. A purposive sampling was used to select the number of participants required who were adolescents who could share their experiences on living with HIV. During the
interviews, the researcher repeated certain phrases and words that were mentioned or expressed by the participants for clarification. Participants were asked to confirm their responses after the interviews to verify the exact information disclosed. This ensured that their accounts were well documented before conclusions were made. Supervisors scrutinised the interviews and were coded independently by the researcher and the supervisor. Additionally, the transcripts were also coded by the researcher and the supervisor and disparities that were identified were reviewed and amended.

Dependability refers to data stability over time and over conditions (Polit, Beck, & Hungler, 2001). Questions were asked in order to elicit the responses that could answer the objectives of the study. Furthermore, the supervisors assisted the researcher in identifying the themes and sub-themes from the data. A detailed audit trail was also kept to enable other researchers to verify the processes undertaken in this study.

Confirmability refers to the neutrality or objectivity of the data (Polit & Beck, 2010). The researcher was mindful of her own attitude, knowledge, and views about the topic under study so that it does not reflect in the participants’ data. To achieve this, the responses of participants were recorded and transcribed verbatim which ensured that the findings were a true reflection of the experiences of the adolescents living with HIV. Direct quotes from the participants were also used to support the themes that emerged. The data were coded by the researcher and her supervisor separately and all discrepancies that occurred were discussed, agreed upon before conclusions were made.

Transferability is the degree to which the findings from the data can be transferred to other settings or groups (Polit & Beck, 2010). This was ensured by giving a thorough description of the research setting or environment which is the Fevers Unit of the Korle Bu Teaching Hospital, methodology, and the number of participants involved and the design
used so that other people studying similar group or setting can replicate it. Characteristics of the participants were also provided. In other words, thick descriptions of the setting and processes involved were kept as field notes for future reference.

3.11 Ethical Considerations

Ethical approval for this study was obtained from the Institutional Review Board of the Noguchi Memorial Institute for Medical Research, University of Ghana, Legon (Appendix D) and the Korle Bu Teaching Hospital (Appendix E). Introductory letter from the School of Nursing (Appendix C) was sent to the Research Unit of the Korle-Bu Teaching Hospital which approved the study (Appendix E). Approval letters were sent to the Head of the Unit and the Deputy Director of Nursing Services in-charge at the Fevers Unit for permission to conduct the study. Subsequently, written consent was sought from the participants before the interview (Appendices G, H & I). An explanation of the study, purpose, objectives of the study, specific expectations concerning participation and potential costs and benefits were explained to the participants. After the discussion of the agreement, all those who agreed to voluntarily participate were given Consent form (Appendix G) which the participants read and signed (participants who were 18 years and above). For those who were less than eighteen (18) years, Parental /Guardian Consent (Appendix H) was sought before the participants voluntarily signed the Child Assent form (Appendix I).

Participants’ privacy was ensured during all the interviews as any information that identified the participants were kept in a locker under lock and key in the custody of the researcher. The audio recordings were stored on a computer with a password only to be accessible to the researcher and her supervisors. Confidentiality was ensured as the venue for the interview provided a conducive environment for the participants and the interview was devoid of intrusion and interruptions which made the participants relaxed. Furthermore,
pseudonyms were used in the demographic data as well as identification codes in the presentation of the findings to protect the identity of the participants. The audio recordings, data and field notes would be kept in the custody of the researcher and her supervisors in a locker for a period of five (5) years after the study and thereafter destroyed according to the tenets of the University of Ghana.
CHAPTER FOUR

FINDINGS

This chapter presents findings on the experiences of adolescents living with HIV at the Fevers Unit, Korle Bu Teaching Hospital. Twelve (12) participants attending the Adolescents and Young Adults’ clinic at the Fevers Unit, Korle Bu Teaching Hospital were interviewed regarding their experiences of being diagnosed with HIV, Antiretroviral therapy (ART), support and coping strategies that they use in order to live with the disease. In-depth interviews were conducted from November 2016 to April 2017 using an interview guide.

Eight main themes emerged from the data with their corresponding sub-themes. Verbatim quotes from the participants were used to emphasise the main themes and the sub-themes. The main themes that emerged were disclosure of illness to family and significant others/ reasons, Anti-Retroviral Therapy (ART), care at the hospital and secrecy. Others were sources of infections/ramifications, selected experiences of adolescents, coping/support and future prospects. Table 4.2 presents a summary of the themes and sub-themes.

The findings are presented using pseudonyms to personalise the verbatim quotes and conceal the identities of the participants. The following are the pseudonyms; each of the participants was identified respectively as P1= Naa, P2= Dankwah, P3= Akwesi, P4= Ebow, P5= Elikem, P6= Jemilatu, P7= Baaba, P8= Nii, P9= Owusuuaa, P10= Ayitey, P11= Kabuki and P12= Akorfa. The profile of the participants consisted of adolescents between the ages of 14 -19 years who were aware of their HIV status as well as on antiretroviral therapy. In-depth interviews were conducted with the participants until saturation was achieved at the 12th sample.
4.1 Demographic Characteristics

Twelve (12) participants were interviewed from the Adolescents and Young Adults’ Clinic of the Fevers Unit. They were all adolescents living with HIV, receiving care and treatment at the Clinic. The participants’ age were between fourteen (14) to nineteen (19) years: two (2) were 14 years, one (1) was 15 years, two (2) were 16 years, two (2) were 17 years and five (5) participants were 19 years. Six (6) males and six (6) females participated in the study. They were all students at different levels of education. Five (5) were in Junior High School (J.H.S), four were in Senior High School (S.H.S), two (2) were S.H.S graduates and one (1) was in a tertiary institution. In terms of ethnicity, six (6) were Akans, three (3) were Ga/Adangme, two (2) were Ewes and one (1) was a Dagomba. Ten participants resided in Accra while the other two were in the Eastern region of Ghana. Ten (10) participants were Christians from different denominations and two were Moslems. All the participants were Ghanaians and they all spoke English during the interview. The participants have been attending the Adolescent and Young Adults’ Clinic from four months to five years. The demographic characteristics have been provided (Appendix I).

4.2 Themes and Sub-themes

Eight (8) main themes and twenty seven (27) sub-themes emerged from the data collected. The main themes and sub-themes are presented in table 4.2 as follows;

Table 4.2: Themes and Sub-theme

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-themes</th>
</tr>
</thead>
</table>
| Disclosure of Illness to Family and Significant Others/Reasons | • Disclosure from Health professionals  
• Reactions of Adolescents, family and Significant others to disclosure  
• Conditions for Disclosure/Reasons for Non-disclosure  
• Intentions of Disclosure to a Future Partner |
| **Anti-Retroviral Therapy (ART)** | • Perceptions of adolescents living with HIV concerning ART  
• The Burden of taking ART/Other drugs for life  
• Side-effects of ART and associated Complaints  
• Non-compliance/Compliance to ART/Consequences |
|-------------------------------|------------------------------------------------|
| **Care at the Hospital**      | • Signs and symptoms experienced by adolescents with HIV  
• Hospitalisation of adolescents with HIV  
• Follow-up/Appointment at the hospital  
• Quality of care at the hospital |
| **Secrecy**                   | • Hiding diagnosis, medications and symptoms from family, friends and significant others  
• Lying about diagnosis, medications and symptoms from family, friends and significant others |
| **Sources of Infection/Ramifications** | • Sources of Infection/consequences  
• Loss of family members  
• Reflections of adolescents with HIV |
| **Selected Experiences of Adolescents** | • Education/School  
• Relationships  
• Financial |
| **Coping/Support**            | • Relaxation/Reducing stress/Hobbies  
• Religion  
• Support |
| **Future Prospects**          | • Career plans  
• Plans of marriage  
• Faith/Hope/Aspirations  
• Future plans |
In the sections that follow, the major and sub-themes are discussed in turns.

4.3 Disclosure of Illness to Family and Significant Others/Reasons

The adolescents were asked about how they got to know about their HIV status, who disclosed it to them and how they (adolescents) disclosed it to their family members and significant others. The reasons behind the disclosure were also explored. Four sub-themes emerged; disclosure from health professionals, reactions of adolescents, family and significant others to disclosure, conditions for disclosure/reasons for non-disclosure and intentions of disclosure to a future partner.

4.3.1 Disclosure by Health Professionals

The responses from the participants, in general, showed that in most cases, the disclosure of their HIV status was done by health professionals namely doctors, nurses and counsellors after requesting for laboratory tests specifically for HIV. The HIV test was carried out after pre-test and post-test counselling were done for the participants before diagnosis were made. The HIV test usually comes out to be positive. All the participants reported that when a positive test was recorded, the health professionals asked about their knowledge on HIV before disclosure was done. Although most of the participants said they got infected at birth, the diagnoses and disclosure were made during the adolescents’ age between 10-19 years. The routine usually involved the request for HIV test which was done before the HIV positive status is confirmed. The following two cases typifies the narratives:

“I had to come to the hospital to do some lab tests and then I was diagnosed. It was a doctor who disclosed my status to me. Some tests were written for me to do and after bringing the results to the doctor, he asked me some questions before telling me. He asked me how I feel and what has been happening to me. Do I see some rashes on my skin and I said yes. Then he said what has been happening to me is as a result of HIV. And that I have HIV.”

P12, 19 years.

“My mother took me to the Korle Bu Teaching Hospital and we came to this place (Fevers Unit). The test was done here and they spoke with my mum
alone and then they later asked me to join her and I was told by the lady (counsellor). A woman in the counselling room (counsellor) told me that I’m HIV positive after the test. That was two years ago. I was 12 years at that time."

**P1, 14 years.**

During the interviews, several participants reported that they asked their parents and guardians for reasons why they were taking some drugs for long periods without any tangible reason. Especially for those who were infected at birth and were started on the treatment at a young age, some participants indicated that their parents brought them to the Fevers Unit for disclosure to be made to them since they (parents/guardians) were not ready to tell them because whenever they questioned their parents, they could not tell them as was the case for the following participants:

In some cases, some parents were able to disclose the HIV status to their adolescent children.

“I was born with the disease. My other siblings don’t have it. I am the only one. I got to know that I have HIV when I was 12 years. I was coming to the clinic but I didn’t know I have HIV. We were twins before one left us. We were two girls and we both had it. It was the doctor who told me at the children’s block that I have HIV. After she saw the lab test results. She told me alone. My mother was waiting outside. The doctor said the test shows that I have HIV so I should be careful the way I do things.”

**P11, 15 years.**

“I have been taking the drugs for a long time but I didn’t know it was for HIV. When I was 12 years, I wanted to know why I was taking the drugs and my mother told me I was too young. She (mother) brought me to the Clinic later and the nurse explained that, the reason why I take the drugs is because I have HIV. She (nurse) told me because my mother said I’m now old enough to know the reason why I take the drugs.”

**P4, 14 years.**

For some participants, certain symptoms brought them to the hospital for HIV test to be done and after testing positive, they were diagnosed and disclosure from the health professional was done:

“I got to know about my HIV status when I was sick and they did a test for me at the hospital. I was then 15 years when I was diagnosed. It was at the Korle Bu Polyclinic. The doctor and the nurse told me after reading my lab report.
They told my father in particular and my father told me at the hospital. It was the woman in the counselling room (counsellor) at the Fevers Unit who explained things to me in detail.”

**P3, 17 years.**

“It was a lady doctor at the Gynae OPD who told me. She (health professional) wrote the tests for me to do at the central lab. When the result was ready, they gave it to me. And after that, they told me that this was what was worrying me and that I have HIV. They told me that there is no medicine to cure the HIV but they have medicine to reduce the viral load.”

**P9, 19 years.**

A participant who was living with close relatives recounted that, he overheard them discussing how to disclose his HIV status to him. He said the relatives took this decision when they realised that he was not adhering to the treatment:

“It was my father (auntie’s husband) who told me but he didn’t tell me face to face. It was like he was talking to my auntie about it and I was at the back of the room and I heard it. My auntie was discussing with my uncle about how to tell me because she didn’t know how to go about it and I heard them. I just heard it from them at home. I was then between 9-10 years.”

**P8, 19 years.**

Another participant also said he found out about his HIV status after going to the hospital for a medical examination in preparation to travel. He said he was counselled before the disclosure was done:

“It was only when I came to the hospital and (eeerm), the doctor told me about my condition. I was then, I think 13 years. I went to the hospital not because I was sick. My dad wanted me to travel so I had to do some medical exams and all that so I went. The doctor counselled me before telling me I have HIV.”

**P10, 17 years.**

4.3.2 Reactions of Adolescents, Family and Significant others to Disclosure

The reactions of the participants, their families, and significant others to the disclosure of the illness were expressed in different forms.
i. Reactions of Adolescents to Disclosure

Most of the participants expressed various forms of emotional reactions when they learned about the illness that they have. The disclosure of their illness/diagnosis brought feelings of sadness, shock, anger, confusion and suicidal thoughts to them. Some participants thought the world was over with them. The participants thought they were too young and could not explain how they got infected. One participant expressed suicidal thought this way:

“Hmm... (Closing her eyes) it was very sad. I didn’t feel very ok. I felt like the world was over with me, I should commit suicide and all those things. I wanted to commit suicide because I was devastated. What went through my mind at that time was to end my life. I couldn’t think straight. Why should this happen to me at this age? I couldn’t explain how I got infected. This made me very sad.”

P1, 14 years.

Other participants said they felt hopeless, sad and cried after their HIV statuses were disclosed to them. Most of the participants did not want to go on with their lives as they saw the illness as the worst thing that could ever happen to them. Some participants could not understand and explain how they got infected because their siblings tested negative. They were confused as they kept asking the question “why me?” As time went on, they decided to take encouragement from the word of God and assure themselves that once they are still alive, there is still hope for them. Excerpts of two adolescents captured the feelings below:

“At that moment I felt like what am I even doing on this earth? I don’t know but that moment I just felt I don’t want to go on again. At that time, I didn’t know anything about it so I was hurt. I had to cry out so I cried out. When I got home, I was crying. I was very sad. Very very sad. It’s not even up to a year when I was diagnosed. I felt very sad. That day was the worst day. I was hurt but it’s nothing. But like as time went on, with God, I felt encouraged. The word of God encouraged me that I am a child of God and that I should proclaim that to myself.”

P12, 19 years.

“When it came, it was like (errrrrm) the first thing that came to mind was why me? Because among all my friends we joke and do all other things so why me. But as usual it has already happened so I have to just live with it. The question
I kept asking myself was why me? That was what was going through my mind. I didn’t plan to do anything bad to myself. I am a Christian and I know once I have Jesus, I have everything even in this situation.”

P5, 19 years.

A male participant expressed his level of confusion and thoughts after his status was disclosed to him:

“When I got to know about my status, I was kind of sad. In the beginning, my thoughts were filled with confusion. How am I going to live with HIV for the rest of my life looking at how small I was? All my siblings were negative and I was the only one who tested positive. Hmmm..., it was a battle in my mind. At that very moment, I was sad and confused. I couldn’t think straight. I was asking myself questions like why me. Why should this happen to me at this time? I just couldn’t understand the whole thing. But after thinking about these things for some time, I had to put myself together. I told myself I need to be strong to battle this illness.”

P2, 19 years.

A few participants indicated that they handled the disclosure well since it was through no fault of theirs that they got infected but they were born with the disease. Therefore, they decided to brace themselves up for the challenges that came with living with HIV:

“I knew that there’s a way to battle it so it wasn’t much of a headache to me. I was not afraid and I didn’t feel guilty because I know, I know I didn’t do anything to get the disease. I was told that it was through birth that I got it so it’s not my fault. So I didn’t feel guilty.”

P2, 19 years.

“I was ok when I got to know. I did nothing at that time. I was just quiet and after that I was just ok. The doctor told me that I was born with it. So I know it has nothing to do with me. My mother also has it but my father doesn’t have it. Hmmm...it is surprising.”

P10, 17 years.

Some participants said their immediate reaction to the news of their HIV status was simply shock. The initial thought was how they might have had the disease. They became sad, shocked and disturbed when they were told that they would be on treatment for the rest
of their lives until a cure is found. One participant explained that he cried because he thought he was too young to have such a disease and thought only adults could get infected with HIV:

“I didn’t do anything at that point in time. It was rather shocking to me so I kept quiet for a very long time and the woman (counsellor) asked me why and I told her I don’t know how I got this disease and where I got it from. She (counsellor) calmed me down and said I will be put on drugs for the rest of my life if a cure does not come anytime soon. This made me sad. When I got home, I cried. I cried because I was too young to have a disease like HIV. I thought it's only adults who get it. I later realised that I don’t have a choice and there is nothing that I can do about it. I just have to accept it.”

P3, 17 years.

Another participant recalled his reaction this way:

“I didn’t understand it at first because one, I know for HIV positive people; they get this kind of disease through blood transfusion, having unprotected sex with someone who has it and using sharp objects of a person who has it. Yes, those kind of things. But as for me, I have never used anything of anyone who has it before. So I was shocked a little bit. I felt very bad, very bad and even disturbed.”

P5, 19 years.

A few adolescents said they did not react in any way because they were either ignorant about the disease or did not understand what it means to be infected with HIV. Again, the disclosure did not allow the diagnosis to have a strong hold on them because the health professionals assured and encouraged them that they will get better once they start the treatment:

“When the doctor and the nurse told me at the polyclinic, I didn’t feel anything because I didn’t understand the whole thing. I just accepted what they told me. The nurse and the doctor also talked to me that I shouldn’t worry and that once I start taking the medicine, I will be ok. I was not happy when I was told and I didn’t think that’s the end of my life because the nurse and the doctor said there is hope for me when they gave me the drugs.”

P3, 17 years.

Another female participant shared that the first time she heard about HIV was the day her HIV status was disclosed to her:
“The time they told me, I didn’t feel anything because I didn’t know anything about the sickness. I didn’t understand so I took it normal. I was 13 years then. At that time, I didn’t understand what HIV was. I have not heard about the disease from anywhere. So for me, it was the first time I heard about it.”

P6, 16 years.

After the disclosure, most of the adolescents said they were able to condition themselves for the challenge ahead by developing a positive attitude of coping by looking at the brighter side of the challenge confronting them:

“(Giggles), when the doctor told me, I didn’t know what to do at that moment and he tried to comfort me and I was like since the harm has been caused, I cannot do anything about it. All I had to do is to take the medicine well and live a good life.”

P5, 19 years.

Another participant, a 17 year old male said his coping mechanism:

“was to come to the hospital regularly as planned and take my medications”

P10, 17 years.

One participant also expressed his gratitude to God for being alive after his mother explained the reason why he was taking the ART. Although he was not happy initially, he accepted his condition:

“I wasn’t too happy at all but I felt okay later when she (mother) told me why I was taking the medicine. Because if I didn’t take the drugs, I would have died a long time ago. Because everybody has a sickness in one area or the other so I know I am not the only sick person. So afterward, I wasn’t angry or sad when she told me that I have this disease.”

P4, 14 years.

A female participant who could not figure out how she got the infected said she eventually decided to abstain from sexual activities and comply with her treatment to enable her cope with her situation:

“I was so sad and angry with everyone around me. Even when my mum was talking to me, I didn’t mind her. I was really disturbed because I didn’t know where this was coming from...I didn’t know the cause whether sexual
activities or other things. So I decided to stay away from sex for some time and also make sure I take my medicines seriously.”

P9, 19 years.

Disclosure initially was received with sadness, shock, anger, confusion and suicidal thoughts. Mechanisms that adolescents developed to cope include treatment adherence, faith in God and non-guilty conscience.

ii. Reactions of Family and Significant Others to Disclosure

Some participants reported that their HIV positive parents did not show any emotional feelings when they were told about their (adolescents) HIV status. The participants reported that their parents just accepted the news and were indifferent about it. Some participants said this reaction could be because their mothers themselves were HIV positive. One participant said her mother encouraged her to adhere to whatever the health professionals told her:

“My mummy wasn’t surprised as I expected her to be. Maybe because she was also positive.”

P1, 14 years.

“She (mother) didn’t react in any way. She was just encouraging me to do whatever they tell me to do.”

P9, 19 years.

Some participants said their parents knew about their HIV status but they did not inform them because they thought they were too young to be told at the time. The parents therefore waited for the appropriate time and age for the adolescents to be told. Most of the participants said their parents believed that they would better understand their condition in their adolescence because they would have attained some level of maturity:

“She (mother) knew about it but she didn’t tell me because the doctor told her to tell me at this age when I get to understand everything. So she wasn’t surprised or anything. She just told me that everything would be fine.”

P10, 17 years.
In contrast, the reactions of HIV negative parents when they learnt about the HIV diagnosis of their adolescent children was devastation. As one participant said his father was devastated and could not believe it especially for a father with an only child to be diagnosed as HIV positive:

“*My dad was devastated. He couldn’t believe it when he was told by my mother because he said I’m an only child and for me to have this condition is not good.*”

P10, 17 years.

Another participant reaffirmed that her mother refused to accept that she (adolescent) was HIV positive and wanted to know where she got the disease from because none of her family members have it:

“So at that time my mother said she will not believe it because she doesn’t have it and none of my family members also have it. She was asking that where did I get it from?”

P6, 16 years.

A mother reacted by crying when she got to know about the daughter’s diagnosis but decided not to explain it to her because she thought she was too young to understand what was going on:

“I was thinking that maybe it was some sickness that my mother is afraid to tell me about. I was worried about the way she was crying but when I ask her, she kept telling me I will not understand what sickness it is.”

P6, 16 years.

The mother of the adolescent went to the extent of seeking alternative treatment for her daughter’s illness. She took her daughter to the sea side to bath with the sea water as an alternative treatment/religiousity for the skin rashes the daughter had. She kept her daughter at home and did not take her to the hospital after the diagnosis was made. The participant explained that the skin rashes she had disappeared after bathing in the sea for three months.
The rashes reappeared on the skin later and when the mother realised its seriousness, she decided to take her to the hospital for treatment:

“But my mother refused to bring me here (hospital) because she said she doesn’t believe it (HIV diagnosis). She kept me at home with the rashes on my body. So she has been sending me to the Labadi beach to bath in the sea. I’ve been bathing there for some time; for about three months and the rashes went. When it went, then it came back again. When she saw that the rashes had come on my skin again and this time it was serious, then she brought me to this place (Fevers Unit).”

P6, 16 years.

Some participants reported that some of their siblings who were told about their diagnosis received the news with shock. But most siblings encouraged and assured the participants and offered them their unflinching support to enable them to live with the illness:

“It was later that my mum told one of my sisters. She was shocked but came to assure me of her full support through this difficult moment.”

P2, 19 years.

Some participants reported that her siblings showed concern and encouraged her to be strong, focus on her studies and live a normal life:

“My siblings are also close to me. They said I am not alone so I should feel free and live my life normal. My mother’s relatives also tell me to be strong and focus on my studies.”

P1, 14 years.

Some participants narrated that family members felt bad, sad, cried and shouted when they heard about the diagnoses of the adolescents. One participant reported that one family member went to do the HIV test in order to be sure it does not “run in the family”. Some family members questioned the mothers of the participants on how they (participants) were infected. The excerpts from the statements of the participants show the expressed sentiments of some family members of the adolescents:
“She (sister) felt very bad when she got to know. Then she asked my mother how I got this sickness and my mother told her because of my father. And that my father transferred it to her and I was born with it.”

P11, 15 years.

“When my auntie heard from my mother that I was HIV positive, she shouted. And she also said she doesn’t believe it because, in their family, no one has that sickness. Even she went to do the test and it was negative. So she was asking that then who gave it to me because I’m young.”

P6, 16 years.

One of the adolescents in the study was encouraged by the mother of her close friend. The adolescent was told to stop crying because she will not die:

“In fact, the day the doctor told me and I told her (friend’s mother), she encouraged me and told me not to cry and that it’s not anything serious. That I will not die and nothing will happen to me.”

P12, 19 years.

A partner of one of the adolescents was surprised when he was told by the girlfriend that she had HIV. He quickly went to do the HIV test which was initially negative. He decided to abstain from sex with the girlfriend until a repeat test was done. The adolescent narrated:

“When I told him that I have HIV, he didn’t say anything. He looked surprised but he didn’t tell me anything. He was quiet. He has also gone to do the test but he is negative. They told him to come and repeat the test in six (6) months’ time. We are still dating but this time we don’t have sex anymore.”

P9, 19 years.

4.3.3 Conditions for Disclosure/Reasons for Non-disclosure

The conditions for disclosure are the conditions under which the adolescents decide to disclose their diagnoses to their families, friends and significant others. The participants outlined reasons why they would disclose or not disclose their HIV status to some family members, friends, and significant others.
i. Conditions for Disclosure

For the adolescents, certain conditions must be present before they could disclose their status to family, friends and significant others. While some said they would never disclose their status to anybody no matter the circumstances, others said they would disclose to people they could trust to keep the diagnosis a secret. The underlining word that ran through the responses of the participants was trust. They told people who had supported them in the past and they know they would be there for them anytime the need arises. Two participants captured this view in the following:

“Seriously, those I chose to tell, I trust them. That is all. Apart from that, nothing else. I realised they could be trusted and they have been there for me all this while so I told them. And I know they will support me anytime the need arises.”

P12, 19 years.

“It is only my step brother that I want to tell because I know he can be trusted.”

P4, 14 years.

Some participants also reported that they would only disclose their status to people who are also HIV positive. They said in this case, they can relate well with that person since they all have the same condition and can understand each other: One participant said:

“I have decided not to tell people about it including my close friend. I may only decide to tell my friend if I find out that he is also HIV positive. Then I know I can relate well to him and tell him. I believe he will understand me since he is also HIV positive. But if he is not HIV positive, there is no way I will tell him. I will never tell. I just don’t want to tell people about it.”

P3, 17 years.

A female participant told the partner of her diagnosis because she thought she might have been infected through sexual activity and that he might also be infected. She told him to do the HIV test:
“The guy I was dating is the only one I have told apart from my mother. Even my elder brother doesn’t know because I’ve not told him. I chose to tell him (partner) because I was thinking that may be if I got it through sexual activity, then he may also have it. So I told him to go and check and even the doctor also told me to tell him to come and check.”

P9, 19 years.

ii. Reasons for non-disclosure

The reasons why the participants would not disclose their diagnoses to family and significant others were explored. The uncertainty about the reaction of family, friends and significant others made it difficult for the participants to disclose their HIV diagnoses for fear of gossips, discrimination and stigmatisation which they did not want to experience. Other reasons given were mistrust in relation to friends because they could spread the news of their HIV status to other people. The participants said they did not want to be labelled as “bad” persons. One participant said:

“No, I will never tell them (friends). I don’t think I will tell them. I’m not sure about that. Hmmm..., I will not tell them because I wouldn't know their reaction towards me after they get to know about it. Some of them can discriminate against me if I tell them. So to be on the safer side, I will not tell them at all.”

P8, 19 years.

Other participants expressed that she will feel bad if others get to know about her HIV status:

“I haven’t told my friends because I don’t trust them (friends). I will never tell them because I don’t know how they will behave towards me when they get to know. They will go and spread to other people. You know, people like gossiping a lot. I will feel sad if others know about it.”

P7, 16 years.

The reasons why most of the adolescents decided not to disclose their HIV status to family members and significant others varied among them. Some of the adolescents said their friends would not want to get close to them when they get to know about their illness. One adolescent reported that a previous behaviour of her friends in relation to her weight loss
made her conclude that they could stigmatise and discriminate against her when they get to know about the illness:

“When I started losing weight, my friends didn’t want to get close to me. From what they did from the beginning when I was slim, I think when they get to know, they will stigmatise and discriminate against me. That’s why I’ve decided not to tell any of them. Not even my best friend.”

P1, 14 years.

Some participants who were in sexual relationships kept their HIV status from their partners for fear of being rejected and abandoned. One sexually active adolescent decided to keep his diagnosis from his partner because he thought she could not keep it a secret:

“No, I haven’t told her (girlfriend) about it (participant sighed). (After a long silence) maybe she cannot keep it a secret.”

P8, 19 years.

Other adolescents were of the view that, they knew that their classmates and most people would not want to get close to them because the illness is HIV:

“I know a lot of people don’t want to come into contact with people living with HIV. I think that if they knew about it, they would have been stigmatising and discriminating. They wouldn’t want to see me close to them at all and this would have affected me greatly.”

P3, 17 years.

Some mothers and close relatives told their adolescents not to disclose their HIV status to specific people such as siblings, close friends and significant others for fear that they might not want to get close to them after learning of their diagnoses. One adolescent said:

“My other siblings do not know about it. I haven’t told them because my mother says I shouldn’t tell them. This is because they will not want me to get close to them when they know about it.”

P11, 15 years.

One male adolescent decided not to tell the elder sister about his illness because he did not trust her not to tell other people. He said his sister could not keep his condition a secret:
“Apart from my auntie and the husband who know about this sickness, my younger sister knows too but the elder sister does not know. I haven’t told my elder sister because her behaviour is not all that good. I don’t trust her. I think she will tell other people about it. (Participant sighed, after a long silence) maybe she cannot keep it a secret.”

P8, 19 years.

Another participant reported that he did not disclose his condition to all his siblings. He explained that only two of his siblings knew about his condition and that of their mother because she is also HIV positive. To him, it would be burdensome for the other two siblings when they find out that he is HIV positive just like their mother: He expressed:

“For my family members, only two of my siblings know about it. For the other two of my siblings who do not know, I don’t want to stress them or something because they know that my mum has it. When they come to know that I have it too, they will be like the problem has been doubled and all those stuff. I want to keep the burden off them and so I keep it to myself.”

P2, 19 years.

Another participant explained that some people are not well informed about HIV and this could make them not want to get close to them. A doctor also told one of the participant not to tell others about her condition. The participant said she will only tell trusted people:

“Because HIV, if someone should even hear of it, especially when the person is not well educated, they may think that it’s a dangerous disease and that you can’t even get close to the person has it. They wouldn’t like to get close to us. So my friends and some other people do not know because the doctor said no one should know about it except some few people I trust.”

P12, 19 years.

An adolescent refused to tell her best friend because she did not know how her reaction would be. Moreover, the friend’s mother advised her not to tell her daughter. She said there was a reason why the friend’s mother did not want her to tell her friend about it:

“My best friend does not know because I haven’t told her. I planned to tell her but her mother said I shouldn’t tell her. My auntie also said I shouldn’t tell
anyone. If I should tell her, who knows how her reaction would be. You can’t tell. Her mother knows her better so if she says I shouldn’t tell her, then that’s it. I don’t know but she can act weird.”

P12, 19 years.

For fear of discrimination and stigmatisation, some of the adolescents decided not to disclose the illness to any other person. The participants did not trust some of their family members and significant others enough to tell them about their condition. Besides, they did not want their conditions to spread to other people, as depicted in the statement below:

“I think that it is only when other people know that I have HIV that they can discriminate or stigmatisate against me and not want me to be close to them. But so far as they don’t know about it, I’m ok.”

P9, 19 years.

On the contrary, a few of the adolescents thought that their relationship with people will determine whether they will be discriminated against or not when their condition is known by others:

I know there is discrimination and stigmatisation against persons living with HIV but I don’t think that even when people get to know about my HIV status, they will do that to me. I think it depends on the kind of relationship that you have with people before they can do certain things to you. But I don’t think my friends will do that if they get to know.”

P10, 17 years.

4.3.4 Intentions of disclosure to a future partner

In this study, most of the adolescents had plans of telling their future partners about their HIV status. According to them, they could not hide this condition from their future partners because they have to know. Adolescents who do not have partners currently intend to tell them when they get one in future. Some of the participants said they had mixed feelings about how their partners would react in future; whether their partners would accept the news or leave them when they get to know about their HIV status. Two of the participants expressed:
“But most of the time, what comes to my mind is to ask myself questions. The question I always ask myself is “when I break this news to my partner in future, will my partner take it? Like it’s a normal thing or she will burst into fury and leave me or hmmm... But I have plans. I know when I grow, when I’m about to marry and all those stuff, I will tell my partner.”

P2, 19 years.

“All I know is that if I decide to have a family in future, definitely they will get to know about my status. That I know very well.”

P5, 19 years.

A fourteen (14) year old participant reported that in future, she would only disclose to her partner if her mother tells her to do so;

“Assuming I have a boyfriend in future, I won’t tell him immediately that I have HIV. I’m going to wait for my mum to tell me the way I should tell him before telling him.”

P1, 14 years.

In order not for the partner to tell other people about his illness, an adolescent responded that he would only tell the partner after marriage. In that case, she would not be able to tell another person. He expressed:

“I plan that I will tell her one day after I’ve gotten married to her. I will tell her after marriage because (participant laughing) at that stage everything would have been in place. I would have already married her so she cannot tell any other person.”

P8, 19 years.

4.4 Antiretroviral Therapy (ART)

This theme covers the treatment/medication that the adolescents take as a result of their HIV status. The four sub-themes that emerged from this theme were perceptions of adolescents living with HIV concerning ART, the burden of taking ART/Other drugs for life, side-effects of ART and associated complaints and non-compliance/compliance with ART/Consequences. The sub-themes are discussed in the section that follows.
4.4.1 Perceptions of adolescents living with HIV concerning ART

Most of the participants shared their views on the antiretroviral therapy. Most of them had good reports about the drug. They had positive responses concerning the ART. They expressed that their disease conditions had improved with the ART and they do not fall ill as often as they used to after they were put on the ART. They agreed that they had not been on admission since they started taking the ART and they felt better because the drug is effective. One adolescent remarked:

“If it weren’t for those drugs and medical care that I receive, probably my situation would have been somewhere down. So I think it’s good. I knew myself that I was someone who gets sick frequently and even when the nurses at the previous hospital see me, they will say I’m a registered member at the children’s ward but after taking the drugs, everything is fine.”

P2, 19 years.

Another participant reiterated that, he has not been on admission after stating the ART:

“The only thing I know is that, I don’t fall sick like I used to. I don’t feel sick after I was diagnosed and started on the drugs. I have not been admitted since that time. I know the drugs are helping me not to fall sick.”

P3, 17 years.

One of the participants reported that, he realised that when he was taking the ART haphazardly, he was getting sick frequently but after he started complying strictly with the ART, he felt better. He expressed:

“The drug has really helped me because when I was not taking it the way I should at first, one, two then I’m sick. Now that I’m taking it very well, I feel alright. The other drugs especially, the blood one (haematinic) helps me to eat well.”

P8, 19 years.

Most of the participants said their health had improved and this is evident from the laboratory results which showed that they were getting better. The adolescents explained that
they had been on the ART from their childhood and it had worked for them. Other participants reported that the signs and symptoms they had such as skin rashes and headaches had all disappeared and they were able to eat well after taking the ART:

“All I know is that I have been on the antiretroviral drugs since I was a child. The medicine has worked for me and I got to know it by the results of the lab tests that I had done. The results show that I’m improving in terms of health and I’m getting better.”

P10, 17 years.

Another participant remarked:

“For the drugs, it has helped me because the skin rashes I had are all gone now and I don’t experience any headache. I’m eating well too.”

P12, 19 years.

4.4.2 The Burden of taking ART/Other drugs for life

Some of the participants started the ART during their childhood although they could not give the exact age at which they started. They spoke of the strict drug regime; taking ART every morning and evening at a specific time as challenging to them. Others complained about the number of tablets they had to take in addition to the ART. A participant complained about the taste of the ART which made it difficult for him to take it:

“For the antiretrovirals, I’ve been taking it from my childhood. My auntie even said I started taking it immediately I was born. I take one in the morning and two in the evening. At first, I didn’t know how to swallow it so I put it in water to dissolve before taking it. That also did not help me because I feel it’s bitter. So they decided to put it in “Banku” (a local maize diet) so that I can swallow it easily. But still, it didn’t work because when I swallow the “Banku” I always leave the drug behind. The tablet is not all that big but its bitterness makes it difficult for me to swallow.”

P8, 19 years.

Generally, the participants reported that, the fact that they would be taking the ART every day for the rest of their lives was a source of worry for them. They always thought about it because they take other drugs beside the ART. They take supplements such as
multivitamins as well as Septrin. They complained about the pill load when the other drugs were added to the ART. On the other hand, they expressed that they had no choice but to encourage themselves to take the ART and other drugs since that is what would help them live in good health:

“But taking drugs in the morning and in the evening is some hectic task for me. In a day, I take six (6) tablets which is a lot. Not all are antiretrovirals. The antiretrovirals are three; one in the morning and two in the evening. I have to take the supplements that is the Vitamins and Septrin in addition. Sometimes when I take the drug or I’m about to take it, and then it will come to my mind that; so will I do this till I die? So I’ve been encouraging myself that I will try.”

P2, 19 years.

Another participant expressed:

“The challenge I have is taking the drug every day for the rest of my life. It is not easy for me because apart from the antiretroviral drugs, I still take the Septrin, Vitafol and Selevite which they said will help me eat well to gain back my weight. I take one tablet in the morning and two tablets in the evening. When I add it to the other drugs, it’s too many but I just have to take it.”

P1, 14 years.

For some participants, in addition to taking medicine every day, some family members and friends were questioning why they took all those drugs. One male adolescent told his family members that those were normal pills that he takes and that he will definitely stop taking them in future. He said he was always firm with the answer that he gives them whenever he is questioned. He expressed:

“It’s not all that easy because for me, taking medicine always and then my family members and especially friends questioning why I’m taking so much drugs, why? Whether its abortion pills or I’m I a pregnant woman who wants to destroy my baby? Then I tell them that it’s just some normal pills that I’m taking. That by all means one day I will stop taking it. After all, it (medicine) was given to me by my doctor. Apart from the antiretroviral drugs, I take blood tonic and Septrin.”

P5, 19 years.
In order to avoid taking a lot of tablets at a time, few participants reported that they spread the medicine at the different times during the day so they could easily take them and not take too many tablets at a time. One of the participants noted:

“I take two tablets of Septrin and one tablet of Vitafol every day in addition to the antiretrovirals. What I do is that because the tablets are about three or four, I take the Septrin and the Vitafol in the afternoon so that I can concentrate on the ART in the morning and evening. This helps me not to take too much medicine at a time.”

P8, 19 years.

Another participant stated that taking the ART interfered with her work so she had to explain it to the doctor to change the time for her after two weeks of initiation of ART. She said she did not want to think about the fact that she would take the ART for a long time. She said:

“The time I was working, I was not able to take the medicine at the right time. I had to take a break from work in order for me to concentrate on taking the medicine. I take it around 12 am because that’s the time I started with. I take one tablet once a day. I explained to the doctor after the first two weeks if I can change the time and he agreed so now I take it at 8 pm. Apart from the antiretrovirals, I also take blood capsules. Sometimes, I don’t even want to think about the fact that I will take the medicine for a long time.”

P9, 19 years.

4.4.3 Side-effects of ART and Associated complaints

Out of the twelve (12) participants, nine (9) reported to have experienced side-effects with the ART whilst the rest said they felt normal anytime they took the drug. The side-effects reported by the participants included headaches, inability to sleep, diarrhoea, nightmares and dizziness. Other side-effects were blisters and skin rashes, body itching, weakness and excessive sleeping. One participant reported she had skin rashes and blisters when she started the ART which stopped afterwards. She also stated that she experienced headaches from time to time and usually took Paracetamol (analgesic) tablets. Other
participants also said they experienced headaches and inability to sleep when they started the ART:

“When I started taking the drugs, I had blisters and skin rashes but it stopped afterwards. Once a while, I have headaches and I take paracetamol and it goes.”

P1, 14 years.

Another participant said:

“I think some headaches and errrrrm sometimes I can’t sleep. I think that’s all I’ve observed ever since I started taking the drugs.”

P2, 19 years.

A few adolescents reported of having nightmares every night which they attributed to the ART. Other participants complained of having weird dreams when they were started on the ART. He said the terrible dreams he had worried him and he could not understand why he kept having the nightmares. This was typified by one adolescent the following statement:

“The only thing I have been going through is that I dream in the night. Every night when I sleep I have terrible dreams and it worries me a lot. I don’t think or worry too much about my condition but I don’t know why I experience these nightmares.”

P3, 17 years.

It was noted among the participants that the experience of nightmares and dizziness was widespread and worrisome as expressed as reiterated by one female participant:

“Initially when I started taking it, I was having weird dreams but now it has stopped. That’s the only thing. I also had dizziness when I started. But the dizziness is still there.”

P12, 19 years.

Another participant said he was not experiencing any side effects when he was started on the ART. However, the ART was changed from one class to another by the doctor. As a result, experienced some side effects such as diarrhoea and headache:

“When I started taking the drugs, I wasn’t experiencing anything. What happened was that later, the doctor changed the drugs for me and that was when I experienced diarrhoea and headaches. The diarrhoea stopped within a
few days but the headache comes once a while. Sometimes I feel some tension within my fingers and toes and I was worried. When I told the doctor, he said it is the drugs and that it will stop with time. So I stopped worrying.”

P4, 14 years.

Some of the side effects were so severe that the ART had to be changed for the participants. A participant reported of experiencing side effects of body itching with severe headaches as well as sleeping in school. These made her worried but an assurance from a health professional allayed her anxiety:

“The first time I started taking it (ART), my body was itching. When the pharmacist gave it to me, she told me that the first day my body will be itching me. So I took it for some time, about a month. The itching continued and they had to change the medicine for me. When I started taking the new one, the itching stopped. I used to have severe headache but sometimes when I take it in the morning, it makes me sleep at school.”

P6, 16 years.

Another participant complained about the weakness she felt whenever she took the ART which made her sleep most of the time. Due to the sleeping, her work was affected for some time. Therefore, she stayed at home for some time until she got used to the drug. She expressed:

“It’s just the weakness that I feel after taking it (ART). When it happens like that, I cannot do anything. I just have to lie down and sleep. This affected my work so I stayed at home for some time to get used to the drug before I started working again.”

P9, 19 years.

4.4.4 Non-compliance/Compliance to ART/Consequences

In relation to non-compliance, some of the participants reported that they stopped taking the ART at a point because they were not given any reason why they were taking the drugs. One participant wondered why she was taking the medicine although she was not ill. Non-compliance was in different forms. Some participants throw the medicine away when
their parents gave it to them or they stopped taking them entirely while others intentionally missed the pills:

“When I started, anytime they give me the medicine I don’t take it because I tell them I’m taking medicine everyday even though I’m not sick. I stopped along the way because I told my mother that I don’t see why I should be taking all these drugs. My mother came and reported the issue to the pharmacist and she spoke to me. Then I had to go back and take the medicine.”

P6, 16 years.

Another male participant said he was not taking the ART continuously:

“At some point, it’s not that I stopped taking it (ART) but when I take it today, tomorrow I will not take it. My auntie didn’t know that I wasn’t taking the drugs as I should.”

P8, 19 years.

Some participants who were non-compliant at a point and went as far as throwing their ART away had to be told why they were on the ART:

“At first, I wasn’t taking the medicine. Even when my mother gives it to me, I throw it away because I didn’t understand why I was taking it. The doctor told my mother to bring me because I wasn’t taking my medicine. So she (doctor) first asked me if I feel sick or something happens to me when I take the medicine and I said no. Then she (doctor) asked me why I’m not taking the medicine. I didn’t say anything. Then she (doctor) said the reason why I’m taking the drugs is because I have a sickness.”

P11, 15 years.

i. Compliance

Some participants who were initially non-compliant to the treatment decided to be compliant after their HIV status were disclosed to them. An explanation from the health professionals on the importance of the ART helped the participants to appreciate the efficacy of the drug. They realised compliance to treatment to be the only way for them to live longer, feel normal and live a good life. The adolescents who were compliant to the ART shared their experiences on how they made sure they took the ART daily at the correct time. They said they were aware of the consequences of non-compliance which could be death.
participants reported that their parents and health professionals explained the importance of the ART and emphasised on the need to be compliant with their treatment which they accepted in good faith. The adolescents said their parents and guardians reminded them and ensured that they take their medicines regularly:

“Because I know that if I didn’t take the drugs I would have died long time ago, I plan to continue to do what I’ve been doing all this time so that I can live longer. I make sure I take my drugs very well. I take two tablets every day. Half tablet in the morning and one and half tablet at the night. The only thing is that my mother always made sure I take it before I sleep so the drugs are with her. When it’s time, she calls to give it to me.”

P4, 14 years.

Some participants expressed that they were told by the health professionals that the ART reduces the viral load but does not cure the HIV, therefore, they have decided to follow the advice of the health professionals and comply with the treatment:

“They (health professionals) told me that there is no medicine to cure the HIV but they have medicine to reduce the viral load. If I take the advice from them (health professionals) and take the medicine continuously, it will help reduce the viral load so that I won’t be falling or getting sick frequently. I plan to take the medicine as I’m told. I take it once every day and it’s just one tablet and the blood capsules which is also once daily.”

P9, 19 years.

4.5 Care at the Hospital

This theme presents the care that the participants received at the hospital as a result of the physiological manifestations of HIV. The four sub-themes that emerged from the theme were signs and symptoms experienced by adolescents with HIV, hospitalisation of adolescents with HIV, follow-up/appointment at the hospital and quality of care at the hospital.
4.5.1 Signs and symptoms experienced by adolescents with HIV

Most of the participants reported of going to seek medical care at the hospital because they were not feeling well. Others reported to the hospital frequently due to recurrence of certain signs and symptoms which were not responding to treatment until an HIV test was requested and done. Signs and symptoms that were reported to the hospital by the participants were; skin rashes, headaches, weight loss, genital lesions and body weakness. These made them report to the hospital for treatment as shown in the statements below:

“I was falling sick from time to time and it got to a time, I was sick for a long time. My dad took me to different hospitals but I did not get well after I was discharged. They kept taking me to the hospital till I was finally diagnosed.”

P3, 17 years.

A female participant expressed:

“I was sick and my mother took me to the hospital and they said it was nothing. When we went home, my mother realised that I had some skin rashes. The rashes appeared all over my body. That was when they decided to do the test for me and it was positive.”

P6, 16 years.

Some participants tried self-medication to lessen the effects of symptoms but their conditions worsened. Other participants reported of being taken to different hospitals for treatment which did not yield any positive outcomes until they were finally diagnosed with HIV. Other participants decided to go to the hospital after failing to treat the signs and symptoms themselves as shown:

“But as time went on, I started feeling weird. Before the diagnosis, I was feeling headaches most of the time and I used to have rashes on my skin and I didn’t understand so that’s it. I treat the rashes by going to the pharmacy to get some ointments to treat it and it goes but it comes back again. I didn’t understand. I thought then it’s something that is in my blood that is causing it so I had to come to the hospital. I was sick and I came to the hospital with headaches and skin rashes and they realised that it was HIV.”

P12, 19 years.
Another female participant who had vulval lesions reported how she attempted treating it before finally seeking medical care:

“Ok, there was a wound (lesions) on my private part (vulva). The first day, my vulva was itching me so I scratched it. That was a Monday. The next day, I didn’t take it serious because I thought it was some boil. So later on I was applying some medicines but still it didn’t work. Even I was not able to walk at a point, I couldn’t sleep in the night. It will pain me aaa…it was about one week time, it was serious so my mum brought me to the Gynae (Gynaecology) OPD.”

P9, 19 years.

A participant had signs and symptoms that were obvious to the people around them who started asking questions about why she was losing weight. This prompted the mother to take her to the hospital for lab test to be done:

“What happened was that, I started losing weight and I became very slim. My friend and teacher asked me if I was ok. Everyone around me wanted to know why I was growing so lean. My mummy took me to a clinic in our area and I was treated but still.”

P1, 14 years.

4.5.2 Hospitalisation of adolescents with HIV

Four participants reported that they were hospitalised at one point or the other. At the time of these admissions, they had not yet been diagnosed with HIV. Others reported of being hospitalised on several occasions with the same complaints which did not improve much.

One of the participants described his stay at the hospital as good because he was treated well by the health professionals who went about their duties professionally:

“I was someone who gets sick frequently and even when the nurses at the Hospital see me, they will say I’m a registered member at the children’s ward. I was falling sick frequently and have been in and out of the hospital without much improvement. The drugs they gave me in the hospital did not help me much. What I can remember now is my last admission at that hospital. I was about thirteen years and I stayed for about a week. I was admitted at the Children’s ward. The care I received from the health care providers was good
as they treated me well, played with me and they went about their duties in a professional way."

P2, 19 years.

Another participant said she did not like her stay at the hospital because her bed was next to another patient who was always vomiting. She reportedly had to endure it until she was discharged from the hospital:

“I’ve been on admission before and that was two years ago. I was in S.H.S. I didn’t like my stay there. It was so bad. I was with one patient who was next to my bed. She was always vomiting and so on but I had to manage it like that. My HIV status was not known at that time. My auntie and pastor were always coming to take care of me.”

P12, 19 years.

One of the male participants said he was admitted by the health professionals when necessary but he could not remember the number of times this happened:

“Sometimes they (health professionals) admit me at the hospital. I can’t remember the number of times I was admitted to the hospital for some time.”

P4, 14 years.

4.5.3 Follow-up/Appointment at the hospital

The participants reported on their follow-up visits to the hospital for review. The adolescents visited the clinic based on appointments. In situations where the participants were unable to come to the clinic for their treatment, their parents did that on their behalf. The adolescents who were less than eighteen years mostly came to the clinic with their parents or guardians. Most of the participants were scheduled every three months whilst others reported every four months. At the clinic, they interacted with the health professionals such as doctors, nurses, counsellors, laboratory technicians and pharmacists. Each health professional had a role to play. The participants reported that they mostly visited the clinic for their Antiretroviral Therapy (ART). At other times, they went to get their laboratory results for their next visit. Some of the participants said:
“I come to the hospital as planned but the thing is that sometimes I go to school so I’m not able to come so during those times my mother comes to take my drugs for me. Anytime I have to come, my mother comes with me.”

P10, 17 years.

“Sometimes they only ask me to come and take my lab results. So I will come all the way from Akosombo just to come and pick my lab. Then two weeks’ time I have to come to the clinic for review.”

P5, 19 years.

4.5.4 Quality of care at the hospital

In relation to the quality of care at the hospital, all the adolescents responded positively on the attitude of the health professionals and described the interactions and quality time that they had for them. Generally, they expressed that the quality of care they received was good. They said they were treated well and respected at the clinic by the staff. The participants observed that the care they received at the hospital has contributed to the improvement in their conditions since they started coming to the clinic. Some participants were also satisfied with the care at the clinic because they meet other adolescents at the clinic and this makes them feel encouraged that they are not alone. They reported that the health professionals at the adolescents and young adults’ clinic are calm, ready to listen to them and answer any question that they may have. The expressions from the participants indicated that, the interactions they had with the health professionals helped them to release tension and pressure that they came to the clinic with. The health care professionals made ample time to talk to them and helped solve any issue that may come up. A male adolescent said:

“I can say the quality of care is good because as soon as I started coming here, I became fine after some few weeks. I don’t fall sick like I used to. I live in Amasaman (a suburb of Accra) but I come to Korle Bu and I want to continue coming here. I feel ok here because anytime I come to the clinic, I meet young people like myself and that makes me to know that I am not the only young person with this sickness.”

P4, 14 years.
One female participant expressed:

“The quality of care is ok with me. The health care providers relax and talk to you. They don’t discourage you, they like you and talk to you to have hope that nothing will happen to you. Even if you are about to die self, the way they will encourage you will let you know that still you have the strength to survive. I’m ok with their attitude.”

P12, 19 years.

However, some of the participants made some observations at the clinic which they thought hindered the quality of care. These were lateness to work by some of the health professionals which makes the participants wait unnecessarily, especially where they had to go back to school after being attended to at the clinic. A participant had this to say:

“The only thing I’ve observed is that sometimes they (health professionals) don’t come to work early and we have to wait for them before they come and see us. Especially, where I have to go to school to write exams and my father has to go to work on that day. Sometimes the nurses explain to us why they delay, but on the whole, I think they are doing a good job.”

P3, 17 years.

Another participant spoke about inadequate doctors (one) at the clinic to attend to them which led to long waiting time. He complained about not getting home on time due to this. He suggested the need for more doctors at the clinic which will reduce the waiting time and the workload on the doctors. Additionally, he spoke on the attitude of some of the health professionals specifically the laboratory technicians as being too harsh. Although the distance to the health facility is far, he continues coming to the adolescents and young adults’ clinic because he is obsessed with the clinic:

“It’s (quality of care) not all that ok. To me, I think it’s good but not all that good. And as we’ve been coming here (clinic), I notice some problems. Being one of the top hospitals in the nation, you need to have so many doctors so that if people come to the clinic, you just have to split them into smaller groups so that they can be seen and then they leave. Not that one doctor will come and then all the patients will be on that doctor. It will be very hectic for the doctor. The doctor will get tired very easily. They have to split up and make so many doctors come in so that it will help us so that they will just discharge us very fast so that we can go home on time. I am close to a hospital.
in Akosombo but I prefer coming here because I’m addicted to this place. Since this is the place I was brought first after testing positive, I have to cope with it. For the staff working in the laboratory, some are harsh, just too harsh.”

P5, 19 years.

An important theme that transcended all the interviews was secrecy. This is presented in the next section.

4.6 Secrecy

Secrecy was an important theme in the responses of all the adolescents concerning their HIV status. Two sub-themes emerged namely; hiding diagnosis, medications and symptoms from family, friends and significant others and lying about diagnosis, medications and symptoms to family, friends and significant others.

4.6.1 Hiding diagnosis, medications and symptoms from family, friends and significant others

All the participants spoke about hiding their diagnoses from friends and significant others with the exception of their close family members. They expressed that within their families, not everyone is aware of their HIV status. They decided to hide their diagnoses for fear of being rejected. One adolescent expressed:

“The plan I had in mind was to find a way of living with this disease and how to take care of myself so that others will not find out. Like my life has now become secretive. Like (errrrrrm) when other people are doing something and I’m to do same, I go somewhere to do my own stuff.”

P2, 19 years.

Another participant said none of his family members know about his HIV status. The only person who knows about his status is the father and he is the only one who brings him (adolescent) to the clinic:
“My stepmother does not know about it (illness). I’m sure all the other siblings would have helped if they knew what I’m going through. My other family members do not know about my illness; both the nuclear and the extended family. My dad is the only one who knows and that’s why he is the only one who brings me to the clinic.”

P3, 17 years.

In school, the participants hide from friends and classmates in order to take their drugs and to avoid their friends questioning them about the drugs. A participant took off the label on the ART container to deceive friends who were curious to know what the drug was for:

“Nobody knows about my sickness in school. I have friends but they don’t know. Any time I come to the clinic and they give me my drugs and I go to school, my friends in class will come and open my bag. What I do is that anytime the drugs are given to me at the pharmacy, I quickly take off the label so that people will not know what drug it is. It does not bother me when my friends open my bag to find the drugs. This is because they won’t know what drug it is because the paper (label) is off.”

P8, 19 years.

One male participant said he hides from his classmate to prevent them from suspecting he has HIV:

“(Hmmm...) in school, they don’t know I have this sickness. So I also do everything possible so that they won’t suspect me. The teachers do not know about the sickness. They know I’ve been going for check-up because my stepfather or my mother will tell them any time we are going to the clinic. My friends and classmates also do not know that I have HIV.”

P4, 14 years.

A participant who lives in another region in Ghana expressed his unwillingness to go back to the hospital in the town after his diagnosis for fear of the repercussions:

“As I said, I live outside Accra with my mum and siblings but I don’t want to go back to the Hospital in the town because people will get to know my HIV status and that will generate a whole lot of issues for me.”

P2, 19 years.
One female participant reported that she was hiding her HIV status from her friends because she believed that one day, a cure would be found. Moreover, she thought there was nothing her friends could do or give to help her if she told them:

“No, I will never tell them (friends) because one day I know it will come to an end when they find medicine for it. I will never tell any of my friends. Even if I tell my friend about it, she is not going to help me or give me anything that will solve this problem for me.”

P6, 19 years.

Some participants kept their HIV status from their partners because they do not want them to know they have such a condition for fear of rejection:

“She (partner) does not know about my HIV status. I haven’t told her about it because I don’t want her to know I have a disease like that.”

P3, 17 years.

4.6.2 Lying about diagnoses, medications and symptoms to family, friends and significant others.

Most of the participants reported that they lied to some family members, friends and teachers about their signs and symptoms as well as their medications when they were questioned. The answer a participant gave when asked about her chronic condition was that she had gastritis and another said she was asthmatic. This was because some participants have obvious signs and symptoms which made people to suspect they were suffering from certain diseases. The participants lied because of fear of gossips; they did not want people to spread rumours about them and their conditions. In order to obtain permission from school to go to the clinic, some participants told their teachers they were going for routine check-up and their parents supported these claims:

“Anytime my dad’s family ask questions like why I’m I slim and all those stuff, my mum will be saying that maybe I have gastritis or ulcer. When I started losing weight, my friend and teacher asked me if I was ok. I told them yes and
that I had gastritis that’s why. Some of them (friends/classmates) are gossips and they like spreading rumours so me, I don’t want to tell them. They mostly ask me that, I fall sick frequently, going for check-ups and all those stuff. I just tell them that headaches or gastritis and I just tell them some lies. My sitting mate in school, I’ve already told her it’s something normal.”

P1, 14 years.

Another adolescent reaffirmed:

“The teachers know that I’m asthmatic and also my mother told them that every three months I will be going for check-up so they understand me. So whenever I tell them I’m going for check-up, they allow me to go.”

P6, 16 years.

Concerning their medications, some participants reported lying to people when they found out they were on a particular treatment. They told them the medicines were for the treatment of other conditions such as pneumonia. Whilst a participant saw secrecy as a challenge, another reported of being questioned about the pill load and he replied by lying to the family and friends that they were normal pills:

“But when someone sees me taking the drugs, I tell them the drugs are for something else. I lie to them. That’s the only challenge; taking the drugs and (errrrrrrrrm) being able to keep it (ART) from others. I hide to take the drugs when no one is around. But even that, some got to know I was taking it so they asked me and I lied to them that it was for something else like pneumonia.”

P2, 19 years.

In this study, the sources of the adolescents’ infection and the consequences were explored. The findings are presented in the ensuing section.

4.7 Sources of Infection/Ramifications

This theme explains how the adolescents got infected with HIV and the outcomes. Three sub-themes that emerged were; sources of Infection/consequences, loss of family members and reflections of adolescents living with HIV.
4.7.1 Source of Infection/consequences

Almost all the participants knew how they got infected with the disease. Most of them reported that they were born with it or were infected at birth. However, some of the participants were not diagnosed immediately they were born. The diagnoses were made in their adolescence:

“I was diagnosed after the death of my mother because I was falling sick from time to time. I was ten (10) years old when my mother died. She (counsellor) told me that from what my dad told her, I was born with the disease.”

P3, 17 years.

A mother of a participant told him how he got infected with HIV:

“My mother told me that I have HIV and that I was born with it. Then she explained that when she gave birth to me, they did a test that showed that I had HIV.”

P4, 14 years.

One participant reported that she got infected through sexual activities with a former partner. She said they had sex without any form of protection. She added that she was not certain if the infection was from her former partner or the current one:

“I have a boyfriend and we used to have sex without condom before I was diagnosed. But after the test, I decided to stay away from sex. I don’t know if I had it from the first guy because I don’t know his HIV status. I think I may have gotten it from sexual practices; like having sexual affair with the first guy without using a condom.”

P9, 19 years.

Some adolescents could not tell the source of the infection because they reported that their parents tested negative to HIV:

“They did the test for my mother and I and they said my mother doesn’t have it but I’m the one who has it (HIV).”

P6, 16 years.
A female adolescent said she does not know the HIV status of her parents:

“But I don’t know if my mother or my father has it. I have not asked them about it. I don’t know how I got it.”

P7, 16 years.

4.7.2 Loss of family members

Most of the participants experienced loss of close family members. The loss included mostly parents; either one or both. In most cases, they lost their fathers and two participants reported the death of both mother and father. One participant reported the death of a father and a sibling (twin). Seven reported the death of a father or mother. Most of the participants lost their parents in their childhood:

“My father died when I was born so I don’t know him. My mother said he died immediately I was born. And she said he died after falling sick for a short time.”

P6, 16 years.

A female participant who lost both her father and a twin sister remarked:

“I don’t have a father. My father died ten years ago. That time, I was small. We were twins before one left us. We were two girls and we both had it (HIV). Because of the sickness, she died. My mother said when she was alive, she was smaller than me. She died when we were two years.”

P11, 15 years.

4.7.3 Reflections of adolescents with HIV

The thoughts of the participants concerning their HIV diagnoses and the consequences became a source of concern as they constantly thought about what the outcome might be. Thoughts about death was prominent as they knew they had lost a father, mother or both parents to HIV. Now that they have the same condition, they worry about their own deaths. A participant thought that death could happen to him at any time following his diagnosis. This created fear in him because his HIV status became a constant reminder of death. The participants kept these thoughts of deaths to themselves and did not want to share
it with anyone. A participant reported that taking the ART regularly reminded him about his own death. He saw death as part of the lives of persons living with HIV. To him, the final decision concerning death rested with God. Another adolescent said thoughts about his condition and its consequences haunt him however, he is grateful to God that although he has such a deadly illness, he has not yet died. The sentiments of some of the adolescents concerning their HIV statuses and thought of death are shown below:

“They said they have tried to get (errrrrrm) solutions to it but still they have not gotten it. Death is part of us and whether we like it or not, we will all die one day. But it is God who decides that this person should go or that person should go (Participant laughing).”

P2, 19 years.

One of the adolescents reiterated:

“But after I thought about everything, I just thank God that I’m still alive even though I have such a deadly sickness.”

P4, 14 years.

4.8 Selected experiences of adolescents with HIV

This theme highlights some key experiences of adolescents with HIV. Three subthemes emerged and these included; education/school, relationships and financial.

4.8.1 Education/school

In relation to education, all the twelve (12) participants were in school at different levels from Junior High School (J.H.S) to tertiary institution. All the participants reportedly tried to live a normal life in school. They reported frequent absenteeism from school due to clinic appointments and follow-up visits. Anytime they had to go for review at the clinic, their teachers were told. Most of them reported that their parents sought permission from the teachers and these were usually granted. The reasons given to the teachers were that they were going for check-up but the details were not explained.
All the teachers understood this and granted the permission. Some of the participants said they reported back to school after being attended to at the clinic in order not to miss the lessons for the day. A participant said she missed school twice every term:

“Errrrrrrm, I try as much as possible to live a normal life in school. But sometimes, I have to go to the hospital for my drugs. It means I cannot go to school that day. So my mummy will tell my teacher that she is taking me to the hospital for check-up. When I come back to school, I get the notes from my friend to copy. For every term, I can miss school like two times.”

P1, 14 years.

Another participant said she told one of her subject teachers that she was asthmatic:

“The day that I have to come to the hospital for my medicine, I just tell the teacher that I’m going for check-up. Our Mathematics teacher is the one I talk to. When I’m coming to the clinic, I don’t go to school at all. The teachers know that I’m asthmatic and also my mother told them that every three months I will be going for check-up so they understand me. Whenever I tell them I’m going for check-up, they allow me to go.”

P6, 16 years.

Some participants who are students in day schools reported living normal lives in school since nobody in their various schools such as teachers, classmates and friends knew about their HIV statuses. Other participants reported hiding when taking the ART to avoid suspicion. A few stated that they take the ART at home in order not to interfere with their school life:

“In school, I’m able to move around and play with my classmates. I mean we are cool. We learn together, play football together and eat together sometimes. We walk together home most of the time. I’m a day student so I don’t have any problem about taking my drugs in school. Like I said, I take my drugs in the evening when I go home from school. And whenever I have to go to the clinic, my dad will ask for permission for me and the teachers always give me.”

P3, 17 years.
One participant who was in a boarding school reported:

“I do my things normally. I don’t want anybody to suspect me. I have classmates and best friends in school. When it’s time to take my medicine, I just go and get it. I make sure there is nobody around then I take it.”

P5, 19 years.

However, another participant who was in a boarding school had difficulty taking his drugs secretly. He described it as balancing his life between being a student and living with HIV:

“The only problem I have with school is balancing; like taking the drugs and how to manage so that they (classmates/friends) will not see me and that’s it.”

P2, years.

A participant stated that absenteeism from school to go to the clinic for follow up affected him:

“The only thing is that, it (absenteeism) has affected my school work because sometimes I have to come to the clinic for medicine so I don’t go to school on that day”

P4, 14 years.

4.8.2 Relationships

With respect to their relationships, six (6) participants reported that they were in relationships with the opposite sex and related well with each other. They described their closeness to their partners and reported treating each other fondly and having fun:

“I am closest to my girlfriend. Our relationship is cordial. We are friends and get along well. (Participant smiling) We talk about issues of life together, we go to interesting places to have fun like the mall.”

P2, 19 years.

A female adolescent also said:

“My boyfriend is very close to me that’s why I was able tell him. He relates to me very well even after I told him, we are still close.”

P9, 19 years.

One participant indicated that she was not dating because the news of her HIV status affected her so much that she decided to hold back. She explained that her former partner
wanted to come back but she was not ready to accept him. She said she needed time to think carefully before taking a decision. She was uncertain about how he would react to her HIV status when he was told. She anticipated he might misunderstand and take the news differently:

“I’m not going out with any guy at the moment. Not now, I’m not ready. I don’t know but after I heard this issue seriously, it affected me. He (partner) was 21 years when we broke up. He is begging though. Begging to come back. But hmmmm….it’s not easy. So right now too, I thought about it. And if I should also tell him that I have HIV, how is his reaction going to be? You understand. And you know guys, some of them don’t really know what it takes to have this (HIV). And they will take it in a different way, you understand so me, I told him I’m not ready now. He should give me some time.”

P12, 19 years.

i. Sexual practices

On the question of sexual practices, three participants shared their experiences. A nineteen (19) year participant reported that his partner is his only sexual partner that he had engaged in sex with on several occasions:

“The sexual relationship I have is with my girlfriend. I have had sex with her several times. Apart from her, I have never had it (sex) with any other person. We started having sex when she told me she wanted me to break her virginity. Then later, she asked me to impregnate her. She said she wants to get pregnant. We enjoy sex a lot so if she does not come to me in Accra, I go to Winneba myself because we have a family house there. I invite her to the house and we have sex”

P8, 19 years.

An eighteen (18) year old participant recounted her experience of meeting her current boyfriend who was initially not close to her. They started having sex which made them close. Not long after being close to her partner, her HIV diagnosis was made. After being diagnosed, they both decided to stop having sex:

“We do have sex from time to time. The issue is that I was dating a guy before I met him (partner) so he is the second guy I’m dating. I met him early January this year (2017). At the beginning, I was not all that close to him. But
later we became close, we were having sex from time to time before I went to do the test so now we don’t have sex. He understands why we should stop.”

P9, 19 years.

One of the participants reported that she was in a sexual relationship with her former partner. They had sex periodically. She said he was the only sexual partner she had and they always had safe sex:

“We were sexually active. Whenever we felt like having sex we do. But one thing is that we were always protecting ourselves every time we had sex. Apart from him, I have never had sex with any other guy.”

P12, 19 years.

ii. Safe sex

With regards to safe sex, all the participants had some knowledge about the topic because they said they have heard about it. The participants who were not in sexual relationships spoke about their future use of condoms to protect their partners from getting infected with Sexually Transmitted Infections (STIs), especially HIV and to prevent unwanted pregnancy. They appeared to understand the importance of condom use in sexual practice:

“I know it has to do with protecting yourself from getting pregnant and also getting STIs. For eg. Syphilis, gonorrhoea or HIV. My mum, dad and siblings have been telling me not to engage myself unless I’m fit to do so like get married or have a boyfriend. We will practice safe sex in future by using a condom in protecting ourselves.”

P1, 14 years

One male participant reaffirmed his future use of condom to prevent infecting his partner with HIV:

“In future if I decide to have a girlfriend and involve myself in any sexual activity, I will protect her by using a condom. This will prevent me from transferring the HIV to another person.”

P4, 14 years.
A participant had knowledge about emergency contraceptive as a means of preventing pregnancy but noted that it does not protect against sexually transmitted infections (STIs). He expressed:

“Safe sex is about using protection or like using condom whilst having sex. And I learnt there is a new one too. And they have a certain drug they take after having sexual intercourse without using a condom. This is the drug they take so that the girl will not get pregnant. But of course I know this one only prevents pregnancy and not Sexually Transmitted Infections (STIs).”

P5, 19 years.

A participant stated that she started using a condom with the boyfriend at the time she did not know about her HIV status. She practiced safe sex because her auntie told her to protect herself with a condom if she wanted to have sex:

“We protected ourselves even when I didn’t know I was HIV positive. For my auntie, she used to work at the hospital so she told me that any time I want to have sex, if I should even have a boyfriend, I should always protect myself. So I was always protecting myself with condom.”

P12, 19 years.

Another participant reported that he practices safe sex with the partner because he is not ready for pregnancy and fatherhood. He said although he and the partner do not like the use of the condom, they had to ensure and insist they practice safe sex in order to protect her. He narrated below:

“I use a condom when we are having sex because I don’t want her to get pregnant and my time is not due to be a father. Safe sex is protecting yourself during sex. I learnt that using a condom will not transmit the virus to her (partner). So I always make sure that I use it every time to protect her. I don’t like using a condom but because I have HIV, I have to use it to protect her. She doesn’t complain about the fact that I always use a condom and she has not asked me why I always use a condom. What she said was that anytime we have sex, she feels a burning sensation in her vagina. When it happens like this, she tells me not to use the condom on her but because I cannot have sex with her without the condom, I just walk out of the room”

P8, 19 years.
iii. Abstinence

Some participants who were not in any relationship and a few in non-sexual relationships stressed on abstinence. They viewed abstinence as the best and surest way to prevent Sexually Transmitted Infections (STIs) and unwanted pregnancies. A participant cited his strong will as a factor which helped him abstain from sex because he did not trust the safety of a condom. He abstained from sexual practice because he thought it was wrong. He also wanted to prevent diseases and unwanted pregnancy:

“(Participant laughing) we don’t practice sex. We believe it is wrong and can result in serious problems. We would rather abstain to prevent diseases and any unwanted pregnancy. You know, I can’t be pressured into sex. (Participant shaking his head) I am strong willed. I have thought about safe sex but the chances of finishing with a condom and coming out safe, I see it to be slim. I don’t see condoms to be safe. It can get burst and all those things. I don’t really think it can protect well. I would rather abstain from sex and stay safe.”

P2, 19 years.

A participant emphasised:

“But assuming I have a girlfriend, I wouldn’t have engaged myself into sex stuff. I would rather abstain. Abstinence is the best and the surest way”

P5, 19 years.

4.8.3 Financial

Financial constraints encountered by adolescents with HIV was one of the issues they had to deal with. Some of their laboratory tests and the ART were free. Moreover, some of the routine drugs they take in addition to the ART are on the National Health Insurance Scheme (NHIS). Notwithstanding, not all of the participants were on the NHIS in order to benefit from this. Complaints about high cost of transport to the clinic were made by a participant who lived outside the Greater Accra region:

“I easily get transportation to this place, usually a straight car. It is just that it costs a lot. Roughly 50 Ghana Cedis. Sometimes they only ask me to come and take my lab results. I will come all the way from Akosombo just to come and
pick my lab. That one, I spend 40 Ghana cedis. Then two weeks’ time I have to come to the clinic for review which will cost 50 Ghana cedis because I have to eat and do other things from this same amount of money. The cost is not easy for me at all.”

P5, 19 years.

A participant complained about the cost of some of the laboratory investigations as being too expensive for him and the family yet he had not registered with the N.H.I.S:

“I am not on any health insurance but if we have to pay for anything, we do just that. For the medicines, we don’t pay anything but some of the labs, we pay and others we don’t pay. The cost of some of the labs are expensive for us.”

P10, 17 years.

For some participants, their older siblings periodically come in to assist their parents with any financial matters. Below are excerpts from the statements from some of the participants:

“My father pays for the transportation anytime we come. Sometimes my older siblings help. The lab tests and my drugs are all paid for by my father.”

P3, 17 years.

“My mother and my big sister support me by giving me money. My sister gives me money any time I’m coming to the hospital. My mother pays my school fees and gives me money for school and any other thing that I need.”

P11, 15 years.

Another participant stated that because of the low income status of her family, she makes beads to sell in order to support herself:

“My family is in the low income level because we are poor. I’m a student and I make beads which I sell to support myself.”

P6, 16 years.

One participant recounted how her Pastor took responsibility for her as soon as she lost both parents. She stated that the pastor was her main support as he started taking care of her from J. H.S as soon as she lost both parents; now she is in a tertiary institution. Her aunt also assists her with other needs:
“After my parents passed away, the person who is really taking care of me is my pastor. With my hospital bills and school fees, my Pastor is taking care of everything. My auntie is the one who maybe assists. I was in J.H.S by then when my parents passed so he took it upon himself that he was going to take me through school. So for everything, my pastor is the one paying for it. Every bill is taken care of by him...”

P12, 19 years.

4.9 Coping/Support

The participants described mechanisms or strategies they put in place to help them deal with the disease after diagnosis. Three sub-themes that emerged under the above theme were relaxation/reducing stress/hobbies, religion and support.

4.9.1 Relaxation/reducing stress/hobbies

All the participants described the activities they engaged in to relax and reduce the stress of living with HIV. They spoke about their hobbies and activities they engaged in when they were free. They engaged in these activities mostly with friends which helped to divert their attention from their current conditions. For the female participants, the activities included watching movies, playing “ampe”, “ludo” reading books, skipping, reading, listening to music and going out with friends: Two participants said:

“I enjoy skipping, playing “ampe”, playing “Ludo” with my friends. I also like engaging myself in all other games that can keep my mind off the stress.”

P1, 14 years.

“I like reading a lot and going out with my friends. I read or I listen to music, but I enjoy reading a lot.”

P12, 19 years.

On the other hand, the male participants engaged in playing football, computer games, watching television, movies, soccer, wrestling and hanging out with friends: Some male participants expressed:
“I mostly go out to play football with friends in my area during my free time. I watch television at home and help my dad with his poultry farm. It keeps me busy at home when school is on vacation.”

P3, 17 years.

“(Participant smiling) Sometimes I like playing games. I like computer games a lot. It helps to take my mind off what I’m going through. I mostly play it with my friends.”

P4, 14 years.

A participant who is an architectural student reported that he used his free time to draw at home because he was also an artist. He said he does not usually go out friends but prefers to stay at home to watch television or listen to music:

“I am an Artist too so sometimes if I’m not doing anything at home, I take the opportunity to draw. I can even paint a picture of you (researcher). I don’t usually go out with friends. I stay at home, do my own things and maybe watch Television and sometimes listen to music.”

P8, 19 years.

4.9.2 Religion

Religion was prominent in this study as all the participants offered prayers to God for healing and to help them withstand their conditions. To them, prayer formed a part of their lives and a means of drawing closer to God. They had the firm belief that God will answer their prayers by healing them of their conditions. Additionally, they prayed and asked God to help them take their drugs. They believed that for them to stay in good health, they had to believe in God. They confessed that although sometimes they were tempted to question God about why he allowed them to be infected with HIV, they quickly affirmed their faith with the word of God as shown below:

“And I also pray to God and I know God will answer me. Who knows, God is able to do exceedingly abundantly above all and can even take this sickness away from me. I pray most times to commit this into God’s hands.”

P2, 19 years.

“Whenever I go to church, I pray and I tell God to help me take my medicine, to get well and He should take the disease out of me.”
Some participants explained that although they were Christians, they do not often go to church but they prayed sometimes to God concerning their illness:

“I don’t often go to church. Sometimes I do pray to God concerning this illness.”

Owusuuaa, 19 years.

A participant who was a Moslem reported that he prayed concerning his future. According to him, he does not know where he would be in future so he would commit it into the hands of Allah (God) believing that his future would be bright. He expressed:

“In some few years to come, I don’t know where I will see myself. It’s all in the hands of Allah. He decides our destinies for us. But I know my future will be bright Insha Allah.”

P10, 17 years.

4.9.3 Support

The encouragement and support that adolescents living with HIV receive from family, health professionals and significant others was explored in this study. Ten (10) participants live with their biological parents (mother, father or both) and two (2) of the participants live with their aunts. The closeness of the participants to their families made it possible for them to be supported. The participants were closer to their parents or guardians than their friends thereby sharing vital information with their families. This enabled their families to easily identify their needs and meet them. Some of the adolescents who were not staying with their biological parents due to orphanhood expressed satisfaction with the close ties they had with their relatives. One participant stated:

“My auntie’s husband is like a father to me. He takes very good care of me. Some people even think he is my biological father. In fact, he is doing well for me. He started taking care of me after my parents died.”

P8, 19 years.
All the participants spoke about the current support that they receive from their families, health professionals and significant others which they duly recognised. They acknowledged the roles played by their families especially parents, aunts, brothers and sisters as very important for their survival. Other participants explained that the Church and their Pastors were also instrumental in terms of the support that they give to them. The support from the family was not only limited to their illness but extended to paying of school fees and encouraging them to learn hard to become better people in future. The support from the family helped them to cope with their conditions. The narrative below typifies the support that they received:

“My mummy keeps encouraging me and telling me not to feel sad. My siblings said I am not alone so I should feel free and live my life normal. My mother’s relatives also tell me to be strong and focus on my studies. My dad’s relatives all support me. They (father’s relative) give money to my mum to help her pay for my labs and drugs. From time to time they send money like every three months or six months. Sometimes, they also send her money to help pay my fees.”

P1 14 years.

Another participant spoke about the support he gets from the father:

“My father always brings me to the clinic for check-up and pays for the transportation anytime we come. Since I was diagnosed, my father has been encouraging me not to think about the disease but to encourage myself because I’m alive and that great things will happen to me in future. Sometimes my elder brother supports me whenever the need arises by paying for my labs and medications when prescribed. My dad encourages me to focus on my studies so that I can achieve all my dreams.”

P3, 17 years.

The support given to the participants by their Aunts and Uncle was to play the parental role so the burden of orphanhood will be lessened. The participants reported that their guardians took care of their needs which they appreciated. Participants’ expressions are shown below:
“My uncle gives me money to buy things for myself and he pays my fees. My auntie buys me books as well as taking care of all my needs. They give me money every day and when I need anything, they also give me. When I was growing up and anytime I fall sick, they were there to help. She (aunt) has been taking care of me since my parents died and she encourages me. My younger sister also supports me.”

P8, 19 years.

“My auntie and pastor were always coming to take care of me when I was on admission. With my hospital bills and everything, it’s my Pastor who is taking care of everything. My auntie is the one who assists. My Pastor pays my fees and everything. For everything, my pastor is the one paying it. Every bill is taken care of by him.”

P12, 19 years.

A participant reported that whenever he was unable to come to the clinic as scheduled, his mother went for the drugs for him:

“Well, my mother is always there to come for my medicines for me and my lab results when I’m in school and not able to come to the hospital as planned. She encourages me to have hope and keep taking the medicine. My dad also supports me with money and other things that I need to make me happy.”

P10, 17 years.

The support from the health care professionals was acknowledged by all the participants. The participants described the support from the health care professionals as financial and emotional support as well as constant encouragement to help them cope with the disease. They spoke highly of the readiness of the health professionals to help:

“The health care workers support me when I come to the clinic by giving me money to use for other things. The last time I came to the clinic, my money got lost and I didn’t have any money for transportation. I asked the woman at the pharmacy (pharmacist) and she gave me some money to take home. I think the way the staff take care of us when we come to the hospital is very good. They are ready to help when you are in need.”

P4, 14 years.

Other participants said the health professionals related well with them by conversing with them to find out if they have any problems. One of the participants said:
“The health care providers’ such as the doctors, nurses, counsellors, pharmacists all relate to me well. Their attitude to me is good. When I come to the clinic, they converse with me and make me feel comfortable. Sometimes, they try to find out from you if you have any problems. I think it’s a good thing. It will help them to know how each of us is doing.”

P1, 14 years.

A participant reported that her teacher supported her in a way by always granting her the permission to go to the Clinic when scheduled. Her friends or classmates made their notes available to her when she was not in school and they were always willing to help her:

“My teachers and classmates/friends relate to me well. When my mummy asks my teacher permission, she always allows me to go. They (classmates/friends) try to help me to get the notes when I’m not in school. My friend is always ready to help me.”

P1, 14 years.

i. Continued support

All the participants appealed for continued support from their families, health professionals and significant others to help them receive the care that they are currently having. They recognised their enormous contributions and wanted them to let the cordial relationship that existed between them continue. A few participants showed the following sentiments:

“For the health care workers, anytime we come to the clinic, they encourage us not to give up but continue to come for review and also take the drugs very well. They are already doing a lot for us at the clinic. So they should continue for us. At school, teachers should continue to teach us to be good boys, learn hard and become a better person. They should open up to us so that when we have any problems, we can talk to them about it freely.”

P3, 17 years.

“What they (family) are doing is enough. They should just continue to support me. Friends also relate to me in a normal way. The health care providers are also good and I’m ok with the environment they create for us when we come to the clinic. The teachers in my school are doing their best to train us. They are good. I think everyone should continue to help and encourage me more to achieve my goals.”

P5, 19 years.
ii. Need for support

All the participants appealed for support from family, friends, health workers, social workers and the entire society. They emphasised on encouragement from all the people who matter in their lives. An appeal was also made by the participants to the society in general to stop the discrimination and stigmatisation of persons living with HIV/AIDS but to get closer and accept them as part of the society so that they do not feel bad or get worse. The adolescents advised the society to embrace persons living with HIV. The participants underscored the need for their friends not to shun them but get close to them. They pleaded with social workers to search and identify persons living with HIV/AIDS in order to encourage and assist them with whatever they might need. Additionally, they wanted the society to put structures in place to make them happy. The participants said they needed collective support and love from family, friends and significant others because they could not deal with the disease on their own. A participant stated that one thing that he needed from his friends was to keep his diagnosis a secret when they get to know about it. He advised the health professionals not to displace their stress on them when under pressure due to the work load. The health care professionals should be calm when attending to them so that they do not become more depressed. He expressed:

“What I need from them (family) is their encouragement. My friends should just make me happy, that’s all. Health care workers should also encourage us like they always do. Social workers can help fish out persons living with HIV/AIDS and help them, feed and encourage them not to give up despite their circumstances. The society should put things in place that can make us happy.”

P12, 19 years.

“My family should support me by giving me all the love, care, protection and all those things. My friends should not shun me but get close to me and see me as one of them. Health workers can support me by encouraging me to have faith and not give up. They should encourage me by telling me that if I take the medicine, I will feel ok but if I don’t, I will get worse and weak. The society
should embrace people living with HIV and bring them close so that they don’t feel bad."

P1, 14 years.

In addition to the support from the family and significant others, another participant spoke about discrimination and stigmatisation of persons living with HIV by appealing to the entire society to desist from it. He expressed:

“My family should be there for me whenever I need them because in this situation, I can’t deal with it alone. It has to be something collective so it’s their support and their love that I need. For my friends, if they come to know, I just want them to be secretive about it. But what I want to tell the health care workers is that in every situation, they should try to be calm because the person (adolescent) coming to them is more depressed. For the entire society, it’s high time they realised that people living with HIV are not different from them. So they should stop the stigma around HIV. They should know that HIV is not an air-borne disease or a disease which can be transmitted through handshakes and all those stuffs or physical contact with an infected person. They should not do anything that will make people feel bad about living with HIV."

P2, 19 years.

iii. Social support networks

Most of the participants agreed they did not know about any social support networks for adolescents living with HIV although a few acknowledged that the existing ones were for adults. They spoke about the “Whatsapp”- social media platform created for them at the clinic to share and discuss information related to their clinic attendance and events organised for them: A participant said:

“I don’t know there are support groups for persons living with HIV and how to find them. My mummy said most of the social support networks are for adults and not for adolescents. The only support group I know is the Whatsapp platform created for the adolescents’ clinic to share information on events, annual get together and educate ourselves. Apart from this, I have not joined any social support group for persons living with HIV. We have a leader on the platform but I don’t play any roles."

P1, 14 years.
However, some participants stated that they had heard about support groups for persons living with HIV. While some had been to the maiden annual get-together for the adolescents but could not make it to the subsequent ones due to the distance and school activities, others said they were yet to go for the programme. This annual social gathering was organised for the adolescents who attend the clinic to have fun and interact with each other. One of the participants mentioned that a social support group should concentrate more on encouraging adolescents, organise fun games for them and take them out occasionally to make them happy. She said:

“I have heard there are groups supporting Persons Living with HIV/AIDS but I haven’t joined any of them. I’ve been to the annual get together for the adolescents once. It was the first one organised for us. But subsequent ones, I was absent. Because I live in Akwatia and school in the same region. Sometimes I will be in school and other times I will be busy.”

P2, 19 years.

One female participant who has never been to the annual get together for the adolescents said:

“I was told at the clinic there are support groups for persons living with HIV. They have a group for adolescents on Whatsapp and they sometimes go for games and stuff. But I am yet to join them for the get together. I have never been to any of the previous ones. I think such a group should be talking to us more often and then encourage us. They should take us out from time to time, organize fun games for us and make us feel happy. We should be made to feel like we have people. Even if I’m not being neglected or something, I should feel ooo...people are around who love me.”

P12, 19 years.

Similarly, another participant corroborated the existence of the annual get together. He said he had been there once but had not been to the subsequent ones. He stated that he had not thought of joining any social support group because he did not want to expose himself to the society that he had HIV. He however expressed interest in forming a support group with
the help of his friends who he met at the clinic. He said they will be sharing information with each other about what the future holds for them:

“I don’t know if there are any social support networks and how to find them. Even if there is one, I wouldn’t have joined because I don’t like showing my face out there in public as someone who has HIV. I’ve been to the annual get together organised for the adolescents once. Subsequent ones I haven’t been there. For me to come again, it will depend on some things. I just made two friends at the clinic and with them, we keep on chatting on Whatsapp. We are trying to form our own group to share information with each other.”

P5, 19 years.

Some of the participants also expressed interest in joining a support group that would be the mouthpiece for all adolescents living with HIV/AIDS. They added that they had intentions of playing roles in the group to help encourage others who find themselves in their situation. They explained that the group will enable them meet and discuss issues that they face as adolescents:

“I would like to join such a group if I find one and become a member. I will love to play roles that will enable me encourage others who find themselves in my situation.”

P2, 19 years.

“But I think if such a group exists, it will be good for us to meet and discuss some issues that we face. We can also learn from others.”

P10, 17 years.

In the ensuing section, the adolescents’ future prospects are presented.

4.10 Future prospects

This theme explored the thoughts of the adolescents with HIV concerning their future. Four sub-themes emerged from the data. These were career plans, plans of marriage, faith/hope/aspirations and future plans.
4.10.1 Career plans

All the participants had positive attitudes towards their future career plans. They all believed they can learn and become important people in their chosen careers through education. An adolescent said:

“My goal for the future is to be a Paediatrician (with smiles). I want to work in the hospital and take care of children and their ailments and meeting the needs of these children. I love children a lot so this is what I want to do.”

P1, 14 years.

Another participant explained that she had to change her career plan from being a nurse to a caterer in future due to her HIV status. She stated that she does not know if her condition would allow her to work as a nurse:

“I wanted to be a nurse but I’ve changed my mind. I have changed my mind because of my current situation. So now, I want to go to a vocational school after J.H.S to learn how to design cakes. But this wasn’t what I really wanted to do from the beginning. Because I don’t know if my sickness will allow me to be a nurse, that’s why.”

P6, 16 years.

One participant reportedly placed her career in the hands of God as he is the decision maker concerning her future. However, she said she would like to move to the international front as a journalist:

“Well, I did my internship at Metro TV so where God will place me, I will be there. For me, in some few years’ time I would like to see myself in one of the media houses. And God willing, some years to come, and if God permits, I would like to go international like BBC, CNN and others. I have a lot of plans. I want to be a news anchor. A news caster for that matter. I’m working at it very seriously that’s why I’m reading Journalism.”

P12, 19 years.
An adolescent reported that his aim is to do his first degree in Ghana and proceed to further his studies abroad. He would like to come back permanently to work especially, when Ghana changes to be like United States in terms of their way of doing things:

“I want to be a clinical psychologist so that I can errm..., because of the stress I’m living with. So when I’m done with the undergraduate, I think I will further my Masters there (United States). I will come back here (Ghana) but I won’t stay for long. I will come back permanently when this place (Ghana) changes to be like that place (United States). Because the environment here I think is not favourable.”

   P2, 19 years.

A participant stated that he wanted to be a footballer in future. He had started training with a team which would help him reach his full potential as a footballer. He hopes to play for an international team in future:

“I want to be a footballer in future so I have been training very well with a team in my area. I will follow this dream after Senior High School. I’m learning and working towards that. I want to play for an international team in future; that’s Real Madrid to be precise.”

   P3, 17 years.

4.10.2 Plans for marriage

All the participants expressed their desire to marry and have a family in future. They acknowledged that they had to tell their future partners about their HIV status. Most of the participants reported that they would not marry a person who is also HIV positive. To them, it is not good option. They do not want to infect their children in future. Some of the participants said they will insist that their future partners test for HIV before they agree to marry them. They expressed in the following statements below:

“I want to have a family in future, I will marry and have only three children. In this case, I have to tell the man that I have HIV. I think I can tell him in future. I don’t think I can marry a man who is also HIV positive because it’s not good. When you want to give birth, the child will also have the disease.”

   P11, 15 years.
"I plan to have a family in future. To have three children. I will make sure that whoever I marry tests for HIV. Although I’m positive, I don’t think I have to marry someone who is also positive. Therefore I will prefer a man who is negative and wants to be with me. If a man wants to marry me in future and I find out he is HIV positive, I won’t marry him. Because it will increase the rate of infection in us if we are both having the HIV."

P9, 19 years.

One male participant who is sexually active said he will marry his partner if she gets pregnant in the course of their relationship:

"I want to marry and have three children in future. I want to marry my partner. We have not discussed it but up till now she is still insisting that I should impregnate her. But she is in school and will soon complete. I told her to wait until we get married. If she gets pregnant along the way, I will marry her. Because I provide for her too so I don’t think that will be a problem."

P8, 19 years.

Only one participant had mixed feelings concerning his marriage plans as he does not know whether his future partner would accept his HIV status or reject him: He shared:

"I have plans of having a family in future. But most of the time, what comes into my mind is to ask myself questions. The question I always ask myself is “when I break this news to my partner in future, will my partner take it? Like it’s a normal thing or she will burst into fury and leave me or hmmm...But I have plans”"

P2, 19 years.

4.10.3 Faith/hope/aspirations

All the participants had faith and hope that what they were going through as a result of their illness would end one day. They aspired to be great personalities in future hence education was seen as the key to the achievement of these dreams. Positive attitude of significant others gave hope to some of the participants. They encouraged and motivated themselves that better days were ahead of them. They had hope and believed that one day, a cure would be found for the HIV:
“I asked one of my friends who was sitting with me in class that if she has a friend who has HIV, will she befriend or get close to the person? She said ah! HIV is nothing, and that she is going to be a friend to that person no matter what happens. That’s what gave me hope and faith.”

P1, 14 years.

“I talk to myself and encourage myself that better days are ahead. That’s the only thing. Mmmm..., and no matter what people say about us, we know that is maybe lack of knowledge that is making them perish. We motivate ourselves, we encourage ourselves so that we will be living a normal life.”

P2, 19 years.

A participant believed that a cure for HIV would be found in future and this will put an end to the illness:

“One day I know it (HIV) will come to an end when they find medicine for it.”

P6, 16 years.

4.10.4 Future plans

Most of the participants had long term future plans aside their career plans. They talked about plans to reach out and extend a helping hand to others, bringing smiles to the faces of HIV positive children where no drug is found to cure the disease. They had plans of setting up humanitarian organisations to help the poor and the destitute or underprivileged. They also plan talking to adolescents who may be going through similar challenges to help them with information about HIV just as it was done for them by others: One female participant expressed:

“I hope to see myself in a high place like working in the hospital and all those stuffs. Taking care of children and helping bring smiles on their faces. I want to be somebody that people will come to when they need information on children. I know I can get there one day.”

P1, 14 years.

Other adolescents who had plans of helping other adolescents living with HIV in future said:
“I want to extend that helping hand. Even if I’m not able to bring that drug or those treatments that will cure the disease, I think I should do something before I die. Like I should reach out to them. I see myself somewhere better than this place in acquiring knowledge to bring back to society. I think the only country in mind is the United States. I know they have the best quality universities there.”

P2, 19 years.

“I will also want to have an organisation that will help the poor and those who don’t have. I will want to also get the opportunity to talk to other adolescents because when I was diagnosed, other people did the same thing for me and now I know a lot more about the sickness than at first.”

P6, 16 years.

4.11 Summary

This study used the biopsychosocial model to explore the experiences of adolescents living with HIV at the Fevers Unit, Korle Bu Teaching Hospital. Twelve (12) adolescents consented and participated in the study after the objectives were explained to them. An interview guide was used to conduct the interviews. The interviews were recorded, transcribed and thematic content analysis was used to analyse the data. The findings indicated that the diagnosis and disclosure of HIV to the adolescents brought a lot of psychological expressions with the challenges of their period of growth which paints a lot of gloomy picture concerning their future. However, the support networks of the adolescents help them to remain in good health and find ways of coping with the disease.

The uncertainty about the reactions of others to their HIV statuses made them keep their diagnoses a secret from some family, friends and significant others. The thoughts of stigma and discrimination made them disclose their diagnosis only to selected members of their families as well as significant others who they trusted. Absenteeism from school was a major challenge in their responses as they report to the hospital for treatment and review.
The findings were consistent with the constructs of the biopsychosocial model of illness. The findings agreed with the notion that a long term illness is biological in origin and cannot be managed medically without the psychological and the social support which will enable the adolescents to cope and have hope to live with the disease. This could explain the reason why the adolescents decided to keep their HIV diagnoses, symptoms and medications a secret from others. Furthermore, the adolescents acknowledged the importance of the support from their family, friends and significant others which was helpful; the coping mechanisms put in place such as prayers, hobbies that helped to relax them and take off the psychological burden of living with a chronic illness like HIV.

The findings of this study would be in detail in the next chapter.
CHAPTER FIVE

DISCUSSION OF FINDINGS

This chapter presents the discussion of key findings of the study in relation to the literature review. The purpose of the study was to explore the experiences of adolescents living with HIV. The discussions focused on the objectives of this study. The study was guided by the biopsychosocial model (Engel, 1981) which states that all issues relating to health and illness are products of a complex interaction of three factors namely biological, psychological and social factors in understanding health and illness. It emphasised the distinct parts of care: the patient; the patient's social context; and the means in place for dealing with illness, namely doctors and the larger system of health care (Engel, 1981b).

5.1 Psychological effects of HIV on adolescents

Disclosure of HIV status to the adolescents was prominent as most parents/guardians brought their children to the hospital for the disclosure to be done by the health professionals. The findings were consistent with findings of a previous study where the caregivers anticipated the healthcare providers to solely tell their children about their HIV status (Kenu et al., 2014; Martinez, Lemos & Hosek, 2012). The disclosure of the HIV status of the adolescents brought about psychological and emotional feelings. Meanwhile, this was aimed by the health professionals and some parents/guardians to help the adolescents to comply with the treatment. This findings are similar to those of (Hodgson, Ross, Haamujompa, & Gitau-Mburu, 2012b) where the diagnosis of the adolescents coupled with being on treatment for life was burdensome to them.

In this study, the participants associated HIV with death although they recognised the contribution of the ART to the improvement of their lives, they were still afraid of death. This
findings is supported by Hodgson et al. (2012b) where the adolescents were worried about dying and this resulted in depression.

The findings of this study showed that, although the adolescents reacted to their HIV status differently, those infected at birth did not blame their parents for their situation but considered it as a challenge that needed to be faced. An adolescent who acquired the disease sexually was able to disclose her HIV status to the mother to gain her support without any feeling of guilt. The findings of this study differs from a previous study where the vulnerability of adolescents was linked to the way they reacted to their HIV status. While those infected sexually found it difficult facing their families due to guilt, those infected by birth were seen to blame their parents for their predicament (Naswa & Marfatia, 2010b).

This study revealed that adolescents with HIV mostly have thoughts about death especially when they know that their parents or siblings died from the same condition. The findings are similar to those from South Africa conducted by (Jena, 2014c) where the adolescents anxious about their own death due to the death of close family members to HIV/AIDS.

Furthermore, the findings from this study showed that, almost all the adolescents were infected from birth but they got to know about their HIV status in their adolescence. The findings of this study corroborate those of Ayres et al., (2006) where the adolescents grew into adolescence without knowing they were HIV positive.

The disclosure was done in their adolescence when they were considered to be matured. This corroborate with another study’s finding where all the adolescents got to know about their HIV status in early adolescence (Jena, 2014c).

Although the adolescents were satisfied with the care received at the clinic, the health professionals focused more on the clinic attendance and adherence to treatment and gave little attention to information on sexual and reproductive health. They wanted to have access
to information so that they can make informed decisions about their sexual relationships. The findings were similar to the study findings where many adolescents were resolute not to let HIV change their lives and wanted to have more information on HIV, sexual and reproductive health but service providers did not sufficiently meet these informational needs (Hodgson et al., 2012b).

All the adolescents in the current study accepted and managed the HIV diagnosis well although their initial reactions were hurtful some of them. This contrasts study findings which indicated that HIV diagnosis can be aggravated if poorly managed due to the trauma associated with the diagnosis (Hodgson et al., 2012b).

Some of the adolescents did not understand the implications of having HIV, the future impact it will have on their lives and the effects on their health. This is similar to findings from a study in which adolescents displayed a poor understanding of the repercussions of HIV/AIDS for their lives. The adolescents were pessimistic toward AIDS care, their future and information about dangers to their health (Abadía-Barrero & Castro, 2006b).

Additionally, the findings from this study revealed the resilience of the adolescents to face the future. They were determined to live a normal life, keep a positive attitude and behaviour despite having been diagnosed with HIV, a disease with such a chronic connotation. This findings is similar to the findings from previous studies ((Galano et al., 2017) which indicated that although HIV is perceived as a stressor, adolescents have plans and projects for the future. They have positive perceptions about the future.

5.2 Social issues affecting adolescents living with HIV

The participants in this study hid and lied about their diagnosis, symptoms and treatment for fear of discrimination and rejection by some family members and significant others. In some cases, they lied to teachers that they were going for routine check-up at the
hospital. The findings agreed with previous study’s findings where the participants lied to the teachers in order to gain permission to go to the hospital for follow up visits which was granted by the teachers (Sarah J. Fielden, Chapman, & Cadell, 2011). The participants’ decision not to disclose their status to some family members, friends and significant others was as a result of lack of trust; the disease was kept a secret by the adolescents in order to avoid the stigma associated with it (Nöstlinger, Bakeera-Kitaka, Buyze, Loos & Buvé, 2015).

In this study, the adolescents put mechanisms in place to live a normal life and shield themselves so that other people would not gossip and shun them because of their HIV status. The findings are consistent with those of Ayres et al. (2006) where the adolescents described that, living a normal life depended on the strategies they put in place to protect their HIV status. They felt comfortable discussing issues and concerns related to their HIV status with health professional but not their significant others.

Most of the participants were instructed by their parents or guardians not to disclose their HIV status to some family members, friends and significant others. The adolescents therefore decided to share their diagnosis and any information about it with only some selected family members and significant others who could be trusted. This was done to prevent them from being rejected and isolated by significant others. The findings of this study confirm a previous study’s findings where most of the adolescents restricted the disclosure of their HIV status to small number of peers and selected adults for fear of their reactions (Michaud et al., 2009).

The adolescents in this study chose not to disclose their HIV status to friends and significant others for fear of being rejected. The findings were in tandem with those of (Jena, 2014c) where the adolescents decided not to tell people outside their family due to fear of rejection, discrimination and stigma associated with their condition. However, some participants kept their diagnosis a secret because they do not want people to subject them to
gossip and spread their HIV status. This corroborates a related study findings where the adolescents kept their HIV status a secret. Disclosure was limited to families for fear of bias, rejection and social segregation (Deacon & Stephney, 2007b; Galano et al., 2017).

The findings from this study also showed that the adolescents’ decision not to disclose their status to some family members and significant others was because of stigma and discrimination. All the participants refused to disclose their HIV status to their friends. All the participants in this study who were in relationships refused to disclose their status to their partners for fear of rejection and those who were sexually active refused to do so for lack of trust and fear of being rejected by their partners (Mutumba et al, 2015). However, those in relationships indicated that they would tell their partners in future when they were ready to marry or when they could trust them. The findings are in line with previous studies (Hodgson et al., 2012b) which shared that stigma could lead to non-disclosure or deferred disclosure to friends or sexual partners. While most of the adolescents shared their status with trusted family members, they were unwilling to tell their friends at school or partners because they did not trust them. This raises ethical issues concerning disclosure of HIV status to significant others especially sexual partners who have the right to this information in order to take decisions about their health (Dixon-Mueller, 2007). There are guidelines on disclosing one’s health condition to a third party, especially sexual partners. Concealing such information from a sexual partner is not the best since it affects their health (Simoni & Pantalone, 2004; Sturdevant et al., 2001).

The participants in this study acknowledged the role of social support networks and groups which are necessary to provide them common fora to interact frequently with each other. They recognised that, support networks can boost their self-confidence. Previous studies from other countries in Sub Saharan Africa which have shared that, support groups help build up confidence in adolescents living with HIV (Hodgson et al., 2012b). However,
these groups were not available to provide such opportunities for the adolescents in this study.

Disclosure was most difficult for the adolescents for fear of rejection and lack of respect if their status is known (Ayres et al., 2006; Bakeera-Kitaka, Nabukeera-Barungi, Nöstlinger, Addy, & Colebunders, 2008). The participants in this study did not see the need to disclose their HIV status to their partners immediately but decided to do that in future although some of them were sexually active in their relationships. In terms of future disclosure, the findings of this study showed that the participants agreed that they would have to disclose their status to their present and future partners at a time when they could be trusted to keep their HIV status a secret. These findings corroborate the study findings by Galano et al. (2017) where the adolescents revealed that, the disclosure of their status had to be shared with their current or future partners; meanwhile, this step is characterised by fear and uncertainty.

5.3 Effects of treatment of HIV on the adolescents.

In this study, all the participants testified about the ART as a very important part of their lives which could prolong their lives if strictly followed. This finding is in tandem with other studies (Bakeera-Kitaka et al., 2008) where children and adolescents had the firm conviction that the ART would help them stay in good health.

Compliance with the ART by the adolescents in this study was not affected by the side effects of the drugs. This finding disagrees with findings of other studies where the undesirable effects of the ART were part of the barriers to compliance (Galano et al., 2017). The findings of this study showed that most of the participants reported various forms of side effects that they experienced with the ART but they were not perturbed because of the positive impact of the ART on their health (Mutumba et al, 2015). All the participants were
on the combination drug regimen (ART) as well as other drugs for the treatment of opportunistic infections which increased the pill load. Although some of the side effects were common to all the participants such as headaches, each adolescent experienced peculiar side effects associated with the drug. Some of the side effects were short term as they disappear after some weeks of ART but others lingered on even after months of the therapy. These findings are consistent with the findings of a previous study by Montessori, Press, Harris, Akagi, and Montaner, (2004) which found that prolonged treatment of HIV with combination regimens could be difficult to sustain because of problems with adherence and toxic effects. All antiretroviral drugs can have both short-term and long-term adverse events. The risk of specific side effects varies from drug to drug, from drug class to drug class, and from patient to patient (Montessori et al., 2004).

The findings of this study also revealed that the participants found it difficult to take the ART as a result of the pill load and strict drug regime which make it challenging for them to adhere to the ART and other drugs. This was supported by the findings from another study (Jena, 2014c) where taking Anti-Retroviral (ARVs) was challenging to the participants due to side effects and strict medication schedules. The adolescents in this study believed in the effectiveness of the medications as it was evident in the improvement of their condition (Mutumba et al., 2015). In terms of family support, the findings showed that their parents or guardians were available and served as treatment supporters to constantly remind them to take their medications. Health care was readily accessible and available as they had enough medications, especially the ART at no cost to them. These findings agreed with the findings of Ankrah et al. where parental support was reportedly one of the main facilitators for adherence to ART. However, these findings contrast previous findings of Naswa and Marfatia (2010b) where many HIV adolescents experienced problems with adhering to ART
regimen due to medication related side-effects, fear and lack of belief in the efficacy of medications, lack of family and social support and unavailable or unreliable access to care.

However, in this study, the adolescents expressed concern about the unavailability of social support networks which would have helped to educate them on the disease and the ART so they could be well informed on HIV. This study’s findings also showed that the adolescents knew that the ART would improve their conditions and help them to live longer. This made them to comply with the treatment. However, those who did not comply initially with the treatment were not aware of their HIV status at the time therefore did not see the reason for being on the treatment. But after the disclosure was done, they accepted their conditions and decided to comply and adhere to the advice of the health professionals in order to stay in good health. These findings disagreed with a previous study’s findings by (Kourrouski & Lima, 2009b). The authors studied medication adherence and here, the adolescents reported that they knew the benefits of the medication to control the disease and to improve their quality of life. However, many of them did not comply with the treatment and rationalised this behaviour by the non-acceptance of the disease.

In the current study, the findings revealed that most of the adolescents recognised the importance and the benefits of the ART although they experienced some side effects. Their parents’ or guardians’ support assisted them to adhere to the ART and the explanations and education on the action of the drugs given by the health professionals was helpful. These findings corroborate the study findings which found that, adherence to treatment by the adolescents rested on family or guardians’ support and the interactions with health providers. The services provided by the health staff and services which are welcoming and encouraging helped adolescents to adhere to their treatment (Hodgson et al, 2012; Mburu et al, 2014).
In the current study, parents did not disclose the HIV status of the adolescents indiscriminately to others. The adolescents living with HIV chose not to disclose their status to their friends. This contrasts other study findings (Mburu et al., 2014b) where family and peers aided adolescents’ adherence to treatment.

5.4 Coping strategies adolescents with HIV use

The participants mentioned that interacting with other adolescents at the clinic gave them strength, hope and encouragement because they knew that they were not alone. This was because they saw other adolescents going through similar experiences which stopped them from feeling depressed and alone. Instead, the adolescents had a sense of belongingness (Jena, 2014c).

The services provided by the health professionals at the adolescent clinic was vital to the participants because they were targeted for their age group. The interactions between the participants and the health professionals made up of doctors, nurses, counsellors, pharmacists and laboratory technicians gave them so much information on their diagnosis and treatment. They were knowledgeable about their condition and how to comply with treatment to stay in good health. The findings were similar to a study that indicated that the interactions between the adolescents and health care providers were mostly positive (Ayres et al., 2006).

However, the participants’ knowledge on their sexual and reproductive health was inadequate and this reflected in the decisions they made in their relationships. The findings differ from other studies conducted in Sub-Saharan Africa which reported an obvious vacuum in the health care system where there were no specialised clinics for adolescents living with HIV (Ferrand et al., 2009; Hodgson et al., 2012b; Jaspan, Li, Johnson, & Bekker, 2009c). These studies indicated that the failure to sufficiently prepare adolescents for healthy sexual decision making could result in greater risk of HIV transmission.
The adolescents acknowledged and appreciated the various forms of support they received from their families and significant others which is similar to the findings of a study where the adolescents valued the reliance on their families for support (Ayres et al., 2006).

In relation to their future prospects, the adolescents aimed and desired for better future irrespective of their HIV status and the uncertainties that came with it. This positive outlook on their lives was similar to previous findings from studies where adolescents living with HIV where they yearned to have careers, families and children in future. They recognised the importance of education as the only means through which they could achieve this and enhance their lives (Bakeera-Kitaka et al., 2008).

The current study showed that, the adolescents looked into the future with hope and positive energy. They looked forward to growing into adulthood, getting married and having their own families. This level of optimism displayed by the adolescents with regards to their career choices and their future responsibilities was supported by the study findings of Mburu et al. (2014).

The findings of this study indicated that there were no organisations that provide psychosocial support for the adolescents apart from what they get from their families. Social workers were completely absent from the lives of the adolescents. These findings contradict the study findings from Zambia where non-governmental organisations (NGOs) provided broad-based livelihood, nutritional and psychosocial services for adolescents living with HIV at the community level (Mburu et al., 2014b).

Notwithstanding, the adolescents were willing to join a social support network because they believed it would be an avenue for them to openly discuss issues concerning them as well as helping other adolescents living with the disease. This confirmed the findings
from a previous studies that social networks have significant bearing on treatment adherence and helps adolescents in coming to terms with their HIV diagnosis (Ferrand et al., 2010). There was recognition of a crucial need to develop and implement programmes to support diagnosis, treatment and care to enhance secondary prevention (Ferrand et al., 2010; Hodgson et al., 2012b).

Additionally, the findings identified shortage of staff at the clinic leading to long waiting time and a lack of adolescent friendly policies to render age-specific care to these adolescents. This is similar to a study finding (Mburu et al., 2014b) which documented staff shortage and lack of health strategies related to adolescents living with HIV as challenges that make it impossible for adolescents to have access to appropriate service.

5.5 Usefulness of the Model

The biopsychosocial model was useful as it fitted the study well and illuminated the experiences that adolescents with HIV go through. The objectives were well explained and findings of the study were discussed in line with the constructs of the model. The various constructs of the model related well to the study findings. The findings showed that illness cannot be discussed in relation to the biological system alone but the interplay of psychological and social factors have an impact on the patient. However, the findings brought an added dimension which is outside the model. The findings revealed two sub-themes namely:

- Religion
- Faith/hope/aspirations

Religion emerged as one of the coping mechanisms used by the adolescents in this study. This was reported consistently in the responses of the participants which helped them in coping with their disease conditions. The religious factor was critical in their lives as they depended on God for survival. They prayed constantly in order to commit their lives, the
disease and their future into the hands of God or Allah with the hope that he would help them to take their medications, live longer and possibly take the disease out of their body systems.

Secondly, faith/hope/aspirations also emerged from the data as a sub-theme. The adolescents had faith and were hopeful that a cure for HIV would be found so that they could come out of their current predicament. They aspired to be great and influential personalities in future in their chosen careers. This was the level of faith displayed by the adolescents in this study.

These could be said to be documented as an extension of the biopsychosocial model of illness.
CHAPTER SIX

SUMMARY, CONCLUSION, IMPLICATIONS AND RECOMMENDATIONS

This chapter presents the summary of the whole research, conclusions and implications. The recommendations have also been documented.

6.1 Summary of the Study

Adolescents living with HIV experience many challenges related to the disease coupled with the complexities of their developmental stage. Although the disease affects the biological system of the adolescent with the effects of long term treatment, the consequences are felt psychologically and socially. These factors can either help the adolescent cope with the disease or worsen their predicament. Therefore, this study aimed to explore the experiences of adolescents living with HIV attending clinic at the Fevers Unit, Korle Bu Teaching Hospital. The purpose was to explore the experiences of these adolescents to inform new strategies and targeted services appropriate for their age.

The study employed a descriptive exploratory qualitative design. An interview guide was developed and the biopsychosocial model of illness was used as the theoretical/conceptual framework of the study.

Twelve (12) adolescents living with HIV between the ages of 14-19 years who attend the clinic at the Fevers Unit were purposively selected for the interview. The interviews were audio recorded and transcribed verbatim. Thematic content analysis was used to analyse the data. Eight major themes emerged from the data which included disclosure of illness to family and significant others/reasons, Anti-Retroviral Therapy (ART), care at the hospital and secrecy. Others included sources of infection/ramifications, selected experiences of adolescents, coping/support and future prospects. The findings showed that the disclosure of HIV to the adolescents brought feelings of sadness, worry and depression to them. They were
determined to adhere to the medical instructions and comply with the treatment to live longer in good health. They kept their diagnoses a secret from some family members and significant others and disclosed it to people they could trust. They expressed the positive effects of the ART on their health. However, the side effects and the strict treatment regime were challenging for them. Family support and encouragement from health professionals helped them to cope with their conditions. The study also found that social support networks were not available but the adolescents found strength in their religious beliefs which helped coping well. Information on sexual and reproductive health were inadequate. Despite all the difficulties they experienced, they were hopeful and positive about the future. They aspired to achieve greatness in their chosen careers through education.

Documenting the experiences of the adolescents will help health care providers better understand and provide the needed care and support that suit the developmental age of the adolescents. It will also help the health care professionals to know the kind of information to give the adolescents that will be relevant to their situation. The study indicates that further research is required in developing an intervention model with respect to the coping strategies that is appropriate for the Ghanaian adolescent living with HIV.

6.2 Implications

The findings from the study had implications for nursing practice, education and research. Implications for the key stake holders such as the Ministry of health/Ghana Health Service, Ghana AIDS Commission and Non-Governmental Organisations have also been documented.

6.2.1 Nursing Practice

The findings from this research indicated that adolescents living with HIV experience a lot of psychosocial stressors. Therefore, Nurses should encourage and support adolescents
living with HIV to take their drugs. The Nurses should be compassionate and understand that, apart from the developmental challenges that the adolescents are going through, they also have a chronic illness. Nurses should attend to their duties in a timely manner to reduce the waiting time of clients/patients. Furthermore, nurses should exhibit professionalism in caring for the adolescents. There should not be discrimination when caring for adolescents living with HIV.

All health professionals should support adolescents to cope with HIV by exhibiting positive attitude of the health professionals especially doctors, nurses and counsellors based on their utterances and the information that is churned out to them. The health professionals should be calm when attending to the adolescents by considering the psychological and social factors surrounding the adolescents which can affect their health positively or negatively.

6.2.2 Nursing Education

Adolescent and reproductive health as well as specialty programmes should be taught by professionals who are well grounded in the subject area, emphasis should be laid on adolescents living with HIV.

In- service training should be organised often for the health professionals to update their knowledge and skills on current trends to deliver quality care to the adolescents.

6.2.3 Nursing Research

Future research can include the caregivers and health professionals to identify their experiences in the Ghanaian context. This can be done as a follow up study to examine the perceptions of all the major players in the lives of adolescents living with HIV. In addition, an intervention study could be conducted to determine which coping mechanism is
appropriate for adolescents living with HIV. Moreover, it is suggested that in future studies, larger sample size can be used in order for the study to be generalised to other settings.

6.2.4 Implications for Policy

The Ministry of health/Ghana Health Service and the Ghana AIDS Commission should make a collaborative effort in ensuring that health care professionals handling the Adolescent and Young adults’ clinic at the Fevers unit at the Korle Bu Teaching Hospital are trained in adolescent, sexual and reproductive health so that they can give timely information to the adolescents. Policies on sexual and reproductive health should be implemented

The Ghana AIDS Commission, National AIDS Control Programme, Non-Governmental Organisations and other relevant bodies must make necessary efforts to form a social support group for the adolescents which will be their official mouthpiece. This will enable them to put their grievances across to the government and also get the needed support and attention to resolve some of their challenges.

Policies should be developed by government in collaboration with relevant bodies to create a fund to give financial assistance to adolescents who have been orphaned through the death of their parents. This will relieve the financial burden on some parents or guardians and help the adolescents to acquire employable skills so that they can cater for themselves in future. All stakeholders should do their best to ensure that policies on Adolescent Reproductive Health are implemented to the latter.

6.3 Limitations of the Study

In this study, bias is possible because it is based on the perceptions of participants which is restricted to an HIV clinic. Secondly, the participants were predominantly Christians which reflected in their responses. Although the participants and their parents were assured of
confidentiality, some of the parents cautioned the participants with respect to their utterances. This may have led to the adolescents withholding some information that would have enriched the findings of the study.

6.4 Recommendations

The following recommendations have been made based on the findings of this study.

**Korle Bu Teaching Hospital**

- Measures must be put in place by the management of the hospital to reduce the waiting time for the adolescents at the clinic so that they can be attended on time since some of them go back to school from the clinic.
- Scheduling of appointments/follow-up visits after school hours, weekends and public holidays to help the adolescents from absenting themselves from school when they have crucial examination and tests to write.
- Health professionals should be trained specially in rendering sexual and reproductive health to adolescents and education given should be age-specific. In particular, health professionals need to be trained to be open and demystify sexuality issues to these adolescents to enhance the success of targeted sexual and reproductive health education to them (adolescents).

**Ghana Health Service/ National AIDS Control Programme/Other Health Service Providers**

- It is recommended that early disclosure should be done for adolescents living with HIV by caregivers and health professionals to reduce the tendency of the adolescents themselves demanding for reasons why they are on ART and being non-compliant.
• It is imperative health professionals know and understand the challenges and difficulties faced by the adolescents in order to help them cope with their conditions as they journey through adolescence. This can be done by providing an avenue to discuss issues affecting the adolescents and also allowing them to express themselves.

• Information on sexual and reproductive health should be made available to the adolescents in the form of leaflets and posters presented in a language they understand and incorporated into their care so that they can make informed choices.

Ghana AIDS Commission/Ministry of Health

• Policies should be formulated with guidelines and to discourage discrimination and stigmatisation of adolescents living with HIV. The policies can be incorporated into the educational syllabus of the Ministry of Education so that the students can be taught in their various schools. Public education should be intensified against discrimination and stigmatisation.

• Adolescents living with HIV should be supported by the National Health Insurance Authority to register with the National Health Insurance Scheme so that they can access all the services covered by the scheme.

• Establishing social support networks outside the clinic for adolescents living with HIV would help them to interact with each other and share experiences. This would help them have a sense of identity and belonging that would lead to enhanced self-worth.

• Training and education of social workers should be provided to assist adolescents in the various communities by visiting and encouraging them to live positively despite their HIV status.
• Specific laboratory tests for adolescents living with HIV should be subsidised as a form of financial relief to them.

Civil Society Organisations (CSOs)

• Guidelines should be developed to help CSOs to manage the disclosure of HIV status to adolescents and their families.

• CSOs should be assisted by the policy makers to provide training to equip adolescents living with HIV with employable skills to reduce the economic hardships on them.

• All stakeholders, including development partners, religious bodies, humanitarian agencies and community support groups should collaborate to identify the needs of adolescents living with HIV and assist them to cope with the disease.

6.5 Conclusion

Adolescents face various challenges as a result of their HIV status coupled with the fact that they are going through a crucial developmental stage in life which comes with its own complexities. The study explored the experiences of adolescents living with HIV. The disclosure of HIV status to the adolescents initially brought emotional reactions such as depression, sadness, suicidal tendencies and despair. However, they were determined to and live their normal life lives by keeping their HIV status a secret. The adolescents hoped to live longer by adhering to the treatment and medical advice from the health care professionals. The adolescents were also ready and poised to do everything possible to ensure that they stay in good health with the help and support of their families and significant others. The health professionals were doing well to give them the needed care but the adolescents had inadequate knowledge on sexual and reproductive health. Therefore, there is a need for the provision of sexual and reproductive health services that is targeted and age-specific to the
adolescents. Furthermore, a formation of a support group for the adolescents will help bring them together to share experiences and information and to strengthen each other.
References


Adolescents Living With HIV


Retrieved from https://books.google.com/books?hl=en&lr=&id=3CNrUbTu6CsC&oi=fnd&pg=PR1&dq=data+analysis+by+Huberman+&ots=LgaZmpVN0h&sig=xBb61H0gQgPPZMGQKrGGZ_S1YC8


APPENDIX A: BACKGROUND INFORMATION FORM

A. Demographic Data

Code Number………………………………

1. Age………………………………………………
2. Sex………………………………………………
3. Occupation……………………………………
4. Level of education……………………………..
5. Ethnicity…………………………………………
6. Religion…………………………………………
7. Residence………………………………………
8. Marital status……………………………………
9. Number of children……………………………
10. Who do you live with?…………………………
11. No. of siblings…………………………………
12. Language (s) spoken…………………………

APPENDIX B: INTERVIEW GUIDE

B. Guiding questions

1. Can you tell me about yourself?

   Probe

   - Schooling, occupation and others
   - Family: family composition, economic status
   - Type of family
   - Head of the family
   - Family relationships/family cohesion
   - Who takes decisions about your health?

2. Can you share with me how you got to know your status?

   Probe

   - Can you describe the day, time, person and place as well as the prevailing circumstances and how the person went about it?
   - Who told you, where, when, under what circumstance?

3. How did you feel when you got to know about your status?

   Probe

   - What did you do? What were your reactions?
   - What did you plan to do?
   - What did you think about? What were your thoughts?
   - Tell me exactly what went through your mind

4. Generally, how has it been like living with HIV?
Probe

- Seeking Medical Care (Access, costs, quality, and distance to care)
- Health Care Providers’ attitudes/behaviour
- Any Hospitalizations? {Describe your stay, care and how you felt as an HIV patient and family support, if any}
- Family and social support
- Reaction of family members- nuclear and extended
- Any support and who supported?
- What was the form of support; regularity?
- School (how do you manage in school?)
- Tell me about how the following relate towards you:- teachers, classmates/friends

Probe

- Discrimination/stigmatization and social problems

5. What have you done as far as disclosure of your illness to your friends is concerned?

Probe

- How did you choose those you told and under what circumstance and how did they react to this information?
- How do your friends relate to you following disclosure?

6. For those who do not know about your HIV status, why have you decided not to disclose to them?
7. Can you tell me about your experience with Antiretroviral Therapy?

8. What challenges/side effects do you experience are associated with the ART?

9. Can you describe or share with me any challenging or distressing experience (s) in your life as a result of your HIV status?

10. Can you share with me about any support group (s) for persons living with HIV?

   Probe

   - How do you find them?
   - Tell me about their activities
   - Membership
   - Any roles

11. Tell me about your close relationships (boyfriend/girlfriend)

   Probe

   - How old is he/she? Does he/she know about your HIV status?
   - How does he/she relate to you?
   - Tell me about any sexual relationships you may have
   - Tell me about the practice of safe sex
   - Tell me about your sexual practices

12. What do you do to relax?

13. What do you think your family, friends, health care professionals, teachers, social workers and the society can do to ensure that you reach your full potential?
Probe

- Specific support from the family, friends, health care professionals, teachers and the society

13. What are your goals and plans for the future?

14. What are your career plans and where do you see yourself in some few years to come?

15. What are your plans concerning having a family?

16. What other thing(s) will you want to tell me?
APPENDIX C: INTRODUCTORY LETTER TO HOSPITAL

UNIVERSITY OF GHANA
SCHOOL OF NURSING

SON/F.11

Ref. No.: ..................................................

November 16, 2016

The Administrator
Institutional Review Board
Korle Bu Teaching Hospital
Accra.

Dear Sir/Madam,

INTRODUCTORY LETTER

This is to introduce to you Gifty Mensah, an M Phil student of the above School and to inform the Institutional Review Board of the approval of the thesis topic “Experiences of Adolescents Living with HIV at the Fevers Unit, Korle Bu Teaching Hospital” by the department of Community Health Nursing, School of Nursing.

Counting on your usual cooperation...

Thank you.

Yours faithfully,

Dr. Mrs. Patience Aniteye
SUPERVISOR

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Tel: +233 (0) 302 513 250 / 0289 531 213
Email: son@chs.ug.edu.gh
Website: www.nursing.ug.edu.gh
APPENDIX D: ETHICAL CLEARANCE LETTER

NOGUCHI MEMORIAL INSTITUTE FOR MEDICAL RESEARCH
Established 1979
A Constituent of the College of Health Sciences
University of Ghana

INSTITUTIONAL REVIEW BOARD
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Telex No: 2256 FUNI GHA

My Ref. No: DE.22
Your Ref. No:

4th January, 2017

ETHICAL CLEARANCE

FEDERALWIDE ASSURANCE FWA 00001824
NMIMR-IRB CPN 022/16-17 amend 2017
IRB 00001276
JORG 00009908

On 4th January, 2017, the Noguchi Memorial Institute for Medical Research (NMIMR) Institutional Review Board (IRB) at a full board meeting conducted continuing review and amended your protocol titled:

TITLE OF PROTOCOL: Experiences of adolescents living with HIV at the Fevers Unit, Korle Bu Teaching Hospital

PRINCIPAL INVESTIGATOR: Gifty Mensah, MPhil Cand.

Please note that a final review report must be submitted to the Board at the completion of the study. Your research records may be audited at any time during or after the implementation.

Any modification of this research project must be submitted to the IRB for review and approval prior to implementation.

Please report all serious adverse events related to this study to NMIMR-IRB within seven days verbally and fourteen days in writing.

This certificate is valid till 3rd January, 2018. You are to submit annual reports for continuing review.

Signature of Chair: ___________________________
Mrs. Chris Dzidric
(NMIMR – IRB, Chair)
APPENDIX E: APPROVAL LETTER FROM HOSPITAL

GIFTY MENSAH
SCHOOL OF NURSING
COLLEGE OF HEALTH SCIENCES
UNIVERSITY OF GHANA, LEGON

13th March, 2017

KOREL BU TEACHING HOSPITAL
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Website: www.kbh.gov.gh

EXPERIENCES OF ADOLESCENTS LIVING WITH HIV AT THE FEVERS UNIT,
KORLE BU TEACHING HOSPITAL

KBTH – IRB /00085/2016

Investigator: Gifty Mensah

13th March, 2017 the Korle-Bu Teaching Hospital Institutional review Board (KBTH IRB) reviewed and
granted approval to the study entitled “Experiences of Adolescents Living with HIV at the Fevers
Unit, Korle Bu Teaching Hospital”

Please note that the Board requires you to submit a final review report on completion of this study to the
KBTH-IRB.

Kindly, note that, any modification/amendment to the approved study protocol without approval from
KBTH-IRB renders this certificate invalid.

Please report all serious adverse events related to this study to KBTH-IRB within seven days verbally and
fourteen days in writing.

This IRB approval is valid till 28th February, 2018. You are to submit annual report for continuing review.

Sincerely regards,

OKYERE BOATENG (MR)
CHAIR (KBTH-IRB)

Cc: The Chief Executive Officer
Korle Bu Teaching Hospital

The Director of Medical Affairs
Korle Bu Teaching Hospital
APPENDIX F: SUPPORT LETTER FROM TRAINED COUNSELLOR

FEVERS UNIT
KORLE BU TEACHING HOSPITAL

14th January, 2017

ACCEPTANCE TO COUNSEL PARTICIPANTS IN A STUDY (EXPERIENCES OF ADOLESCENTS LIVING WITH HIV AT THE FEVERS UNIT, KBTH)

I write in response to your request for me to counsel participants in your study who might be emotionally distressed as a result of the interviews. I accept to intervene appropriately if such a situation arises.

Yours faithfully,

MIRIAM AMA SAM
APPENDIX G: CONSENT FORM

Title: Experiences of adolescents living with HIV at the Fevers Unit, Korle Bu Teaching Hospital.

Principal Investigator: Gifty Mensah

Address: University of Ghana, College of Health Sciences
School of Nursing and Midwifery
P. O. Box LG 43, Legon
giftynunamensah@gmail.com

General Information about Research

Dear Participant,

I am a graduate nursing student from the School of Nursing, University of Ghana, Legon. I am carrying out a research and would like you to take part. The purpose of my study is to seek for information from adolescents living with HIV (14 to 19 years) to help me understand what you go through. I will have a one-on-one discussion with you either in English or “Akan” depending on your choice of language. There is nothing like right or wrong answer and you can answer in your own words. The duration for the interview will be between 45 to 60 minutes. The discussion will focus on what you have been through after being diagnosed with HIV. You will be asked to either sign or thumbprint a consent form. The conversation will be recorded on tape with your permission and your parent/guardian’s permission (for those less than 18 years). The interview will be written in words. Your name will not be
recorded on the tape or written anywhere on any document in this study. A number or false name will be assigned to your conversation. The only people who will have access to our conversation will be my supervisors. The information will be kept under lock and key for about 5 years after the study and thereafter destroyed.

Possible Risks and Discomforts

This study is not expected to pose any risks and discomforts to you as a participant, but due to the sensitive nature of the study which is on HIV, there may be emotional discomfort when you are describing your lived experiences. The researcher will provide the services of a trained Counsellor to support without any payments. (Counsellor, Miss Miriam Ama Sam, Telephone: 0248040553, Fevers Unit, Korle Bu Teaching Hospital). The findings of this research will be published in academic journals and presented at research conferences. However, data will always be presented as group data hence no individual participants will be identified.

Possible Benefits

This research may not provide immediate benefit(s), however I hope and expect that your experiences will inform policy makers and health workers in to appreciate the specific needs of adolescents living with HIV. This will enable health workers to relevant bodies and institutions involved to organize programmes designed to meet the needs of adolescents living with HIV.

Confidentiality

The information you will give about yourself will be protected and not disclosed to other people. Your name and identity will not be written on any document used in this study or appear in the report of this study.
Information from this study will be stored and protected in a cabinet under lock and key in the custody of the researcher in her home. The audiotapes will be stored on a computer with a password only to be accessible to the researcher and her supervisors. The information will be kept under lock and key for about five (5) years after the study and thereafter destroyed.

**Compensation**

You will not be given any monetary compensation for participating in this study. You will be provided with soft drink (coca-cola) and transportation (Fifteen Ghana cedis) at the end of the interview.

**Voluntary Participation and Right to Leave the Research**

You have the right to take part in this study willingly or decline to take part or withdraw from the study at any stage. Your decision not to participate in this research or withdraw will not attract any penalty or affect the care or treatment you are receiving at the clinic. You have the freedom to leave the study at any point during the study even after you have agreed to participate and this will affect the service you receive from health care providers.

**Contacts for Additional Information**

If you have any concerns, answers to pertinent questions about the research and whom to contact in case of research-related injury, you may send an Email or call the researcher or her supervisors using the following addresses and telephone numbers:

Gifty Mensah, giftynunamensah@gmail.com Phone number: 0247416366/0503662194

Dr. Patience Aniteye: patienceaniteye@yahoo.com Phone number: 0244681352
Your rights as a Participant

This research has been reviewed and approved by the Institutional Review Board of Noguchi Memorial Institute for Medical Research (NMIMR-IRB). If you have any questions about your rights as a research participant you can contact the IRB Office between the hours of 8am-5pm through the landline 0302916438 or email addresses: nirb@noguchi.ug.edu.gh

VOLUNTEER AGREEMENT

The above document describing the benefits, risks and procedures for the research title (Experiences of adolescents living with HIV at the Fevers Unit, Korle Bu Teaching Hospital) has been read and explained to me. I have been given an opportunity to have any questions about the research answered to my satisfaction. I agree to participate as a volunteer.

_________________________  ______________________________
Date  Name and signature or mark of volunteer

If volunteers cannot read the form themselves, a witness must sign here:

I was present while the benefits, risks and procedures were read to the volunteer. All questions were answered and the volunteer has agreed to take part in the research.

_________________________  ______________________________
Date  Name and signature of witness
I certify that the nature and purpose, the potential benefits, and possible risks associated with participating in this research have been explained to the above individual.

_______________________                                _________________________________
Date                                                                   Name Signature of Person Who Obtained Consent
APPENDIX H: PARENTAL CONSENT FORM

Title: Experiences of adolescents living with HIV in a Clinic in Accra

Principal Investigator: Gifty Mensah

Address: University of Ghana, College of Health Sciences, School of Nursing, P. O. Box LG 43, Legon.

General Information about Research

I am a graduate nursing student from the School of Nursing, University of Ghana, Legon. I am carrying out a research and would like your child to take part. The purpose of my study is to seek for information from adolescents living with HIV (14 to 19 years) to help me understand what they go through. I will have a one-on-one discussion with your child either in English or “Akan” depending on their choice of language.

There is nothing like right or wrong answer and you can answer in your own words. The duration for the interview will be between 45 to 60 minutes. The discussion will focus on what the child has been through after being diagnosed with HIV. The child will be asked to either sign or thumb-print a consent form. The conversation will be recorded on tape with your child’s permission and your permission as a parent/guardian (for those less than 18 years). The interview will be transcribed into words. Your child’s name will not be recorded on the tape or written anywhere on any document in this study. A number or false name will be assigned to your child’s conversation. The only people who will have access to this conversation will be my supervisors. The information will be kept under lock and key for about five (5) years after the study and thereafter destroyed.
Possible Risks and Discomforts

This study is not expected to pose any risks and discomforts to your child as a participant, but due to the sensitive nature of the study which is on HIV, there may be emotional discomfort when describing his/her experiences. The researcher will provide the services of a trained Counsellor to support without any payments. (Counsellor, Miss Miriam Ama Sam, Telephone: 0248040553, Fevers Unit, Korle Bu Teaching Hospital). The findings of this research will be published in academic journals and presented at research conferences. However, data will always be presented as group data hence no individual participants will be identified.

Possible Benefits

This study may not provide immediate benefit(s) however, I hope and expect that your child’s experiences will inform policy makers and health workers in to appreciate the specific needs of adolescents living with HIV. This will enable health workers to relevant bodies and institutions involved to organize programmes designed to meet the needs of adolescents living with HIV.

Confidentiality

The information you will give about yourself will be protected and not disclosed to other people. Your name and identity will not be written on any document used in this study or appear in the report of this study. Your child will not be named in any reports. Some staff of the Fevers Unit, Korle Bu teaching hospital, School of Nursing and National AIDS Control Programme may sometimes look at your child’s research records. Information from this study will be stored and protected in a cabinet under lock and key in the custody of the researcher in her home. The audiotapes will be stored on a computer with a password only to
be accessible to the researcher and her supervisors. The audiotapes will be kept in the custody of the researcher and her supervisors for a period of five (5) years after the study and thereafter destroyed.

Compensation

Your child will not be given any monetary compensation for participating in this study. He/she will be provided with a soft drink (coca-cola) and transportation (Fifteen Ghana cedis) at the end of the interview.

Voluntary Participation and Right to Leave the Research

Your child has the right to take part in this study willingly or decline to take part or withdraw from the study at any stage. His/her decision not to participate in this research or withdraw will not attract any penalty or affect the care or treatment he/she is receiving at the clinic. He/she has the freedom to leave the study at any point even after he/she has agreed to participate and this will not affect the service he/she will receive from health care providers.

Contacts for Additional Information

If you have any concerns, answers to pertinent questions about the research and whom to contact in case of research-related injury, you may send an Email or call the researcher or her supervisors using the following addresses and telephone numbers:

Gifty Mensah, giftynunamensah@gmail.com Phone number: 0247416366/0503662194

Dr. Patience Aniteye: patienceaniteye@yahoo.com Phone number: 0244681352

Dr. Daniel Arhinful, darhinful@gmail.com/darhinful@noguchi.ug.edu.gh phone number 0244932139.
Thank you.

**Your Child’s Rights as a Participant**

This research has been reviewed and approved by the Noguchi Memorial Institute for Medical Research Institutional Review Board (NMIMR-IRB). If you have any questions about your child’s rights as a research participant you can contact the IRB Office between the hours of 8am-5pm through the landline 0302916438 or email addresses: nirb@noguchi.ug.edu.gh

**VOLUNTEER AGREEMENT**

The above document describing the benefits, risks and procedures for the research title *(Experiences of adolescents living with HIV at the Fevers Unit, Korle Bu Teaching Hospital)* has been read and explained to me. I have been given an opportunity to have any questions about the research answered to my satisfaction. I agree that my child should participate as a volunteer.

________________               __________________________
Date                          Name and signature or mark of parent or guardian

If volunteers cannot read the form themselves, a witness must sign here:

I was present while the benefits, risks and procedures were read to the child’s parent or guardian. All questions were answered and the child’s parent has agreed that his or her child should take part in the research.

________________               __________________________
Date                          Name and signature of witness
I certify that the nature and purpose, the potential benefits, and possible risks associated with participating in this research have been explained to the above individual.

_________________                                                ________________________
Date                                                Name Signature of Person Who Obtained Consent
APPENDIX I: CHILD ASSENT FORM

Introduction

My name is Gifty Mensah and I am from the School of Nursing at the University of Ghana. I am conducting a research study entitled Experiences of adolescents living with HIV at the Fevers Unit, Korle Bu Teaching Hospital. I am asking you to take part in this research study because I am trying to learn more about what you go through as a result of your HIV status and how you are able to cope. This will take forty five (45) to sixty (60) minutes.

General Information

If you agree to be in this study, I will ask you to have a one-on-one discussion with me either in English or “Akan” depending on your choice of language. There is nothing like a right or wrong answer and you can answer in your own words. The duration for the interview will be between 45 to 60 minutes. The discussion will focus on what you have been through after being diagnosed with HIV. I will be ask you to either sign or thumb-print a consent form. The conversation will be recorded on tape with your permission and your parent/guardian’s permission (for those less than 18 years). The interview will be transcribed in words. Your name will not be recorded on the tape or written anywhere on any document in this study. A number or false name will be assigned to your conversation. The only people who will have access to our conversation will be my supervisors. The information will be kept under lock and key for about 5 years after the study and thereafter destroyed.

Possible Benefits

Your participation in this study will provide information will inform policy makers and health workers on how to appreciate the specific needs of adolescents living with HIV. This
will enable health workers, relevant bodies and institutions involved to organize programmes designed to meet the needs of adolescents living with HIV.

Possible Risks and Discomforts

However, the risks associated are emotional discomfort when you are describing your experiences. This may be due to the sensitive nature of the interview. The researcher will provide the services of a trained Counsellor to support you without any payments. (Counsellor, Miss Miriam Ama Sam, Telephone: 0248040553, Fevers Unit, Korle Bu Teaching Hospital). The findings of this research will be published in academic journals and presented at research conferences. However, data will always be presented as group data hence no individual participants will be identified.

Voluntary Participation and Right to Leave the Research

You can stop participating at any time if you feel uncomfortable. No one will be angry with you if you do not want to participate.

Confidentiality

Your information will be kept confidential. No one will be able to know how you responded to the questions and your information will be anonymous. Information from this study will be stored and protected in a cabinet under lock and key in the custody of the researcher in her home. The audiotapes will be stored on a computer with a password only to be accessible to the researcher and her supervisors. The audiotapes will be kept in the custody of the researcher and her supervisors for a period of five (5) years after the study and thereafter destroyed.
Contacts for Additional Information

You may ask me any questions about this study. You can call me at any time 0247416366/0503662194 or talk to me the next time you see me.

Please talk about this study with your parents before you decide whether or not to participate. I will also ask permission from your parents before you are enrolled into the study. Even if your parents say “yes” you can still decide not to participate.

Your rights as a Participant

This research has been reviewed and approved by the Institutional Review Board of Noguchi Memorial Institute for Medical Research (NMIMR-IRB). If you have any questions about your rights as a research participant you can contact the IRB Office between the hours of 8am-5pm through the landline 0302916438 or email addresses: nirb@noguchi.ug.edu.gh

VOLUNTARY AGREEMENT

By making a mark or thumb printing below, it means that you understand and know the issues concerning this research study. If you do not want to participate in this study, please do not sign this assent form. You and your parents will be given a copy of this form after you have signed it.

This assent form which describes the benefits, risks and procedures for the research titled experiences of adolescents living with HIV has been read and or explained to me. I have been given an opportunity to have any questions about the research answered to my satisfaction. I agree to participate.
## APPENDIX J: GENERAL PROFILE OF PARTICIPANTS

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Sex</th>
<th>Occupation</th>
<th>Educational level</th>
<th>Religion</th>
<th>Ethnicity</th>
<th>Stays with:</th>
<th>No. of siblings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Naa</td>
<td>14</td>
<td>female</td>
<td>student</td>
<td>J.H.S</td>
<td>Christian</td>
<td>Ga</td>
<td>Mother</td>
<td>Three</td>
</tr>
<tr>
<td>Dankwah</td>
<td>19</td>
<td>male</td>
<td>student</td>
<td>S.H.S</td>
<td>Christian</td>
<td>Akan</td>
<td>Mother</td>
<td>Three</td>
</tr>
<tr>
<td>Akwesi</td>
<td>17</td>
<td>male</td>
<td>student</td>
<td>S.H.S</td>
<td>Christian</td>
<td>Akan</td>
<td>Father</td>
<td>Three</td>
</tr>
<tr>
<td>Ebow</td>
<td>14</td>
<td>male</td>
<td>student</td>
<td>J.H.S</td>
<td>Christian</td>
<td>Fante</td>
<td>Mother/stepfather</td>
<td>One</td>
</tr>
<tr>
<td>Elikem</td>
<td>19</td>
<td>male</td>
<td>student</td>
<td>S.H.S</td>
<td>Christian</td>
<td>Ewe</td>
<td>Parents</td>
<td>Three</td>
</tr>
<tr>
<td>Jemilatu</td>
<td>16</td>
<td>female</td>
<td>student</td>
<td>J.H.S</td>
<td>Moslem</td>
<td>Dagomba</td>
<td>Mother</td>
<td>One</td>
</tr>
<tr>
<td>Baaba</td>
<td>16</td>
<td>female</td>
<td>student</td>
<td>J.H.S</td>
<td>Christian</td>
<td>Fante</td>
<td>Parents</td>
<td>Three</td>
</tr>
<tr>
<td>Nii</td>
<td>19</td>
<td>male</td>
<td>student</td>
<td>S.H.S</td>
<td>Christian</td>
<td>Ga</td>
<td>Auntie</td>
<td>Two</td>
</tr>
<tr>
<td>Owusuua</td>
<td>19</td>
<td>female</td>
<td>student</td>
<td>S.H.S</td>
<td>Christian</td>
<td>Akan</td>
<td>Mother</td>
<td>Five</td>
</tr>
<tr>
<td>Ayitey</td>
<td>17</td>
<td>male</td>
<td>student</td>
<td>S.H.S</td>
<td>Moslem</td>
<td>Ga</td>
<td>Parents</td>
<td>None</td>
</tr>
<tr>
<td>Kabuki</td>
<td>15</td>
<td>female</td>
<td>student</td>
<td>J.H.S</td>
<td>Christian</td>
<td>Adangme</td>
<td>Mother</td>
<td>Four</td>
</tr>
<tr>
<td>Akorfa</td>
<td>19</td>
<td>female</td>
<td>student</td>
<td>Tertiary</td>
<td>Christian</td>
<td>Ewe</td>
<td>Auntie</td>
<td>None</td>
</tr>
</tbody>
</table>
## APPENDIX K: THEMATIC CODE FRAME

<table>
<thead>
<tr>
<th>THEMES AND SUB-THEMES</th>
<th>ABBREVIATIONS</th>
<th>MEANING/DESCRIPTION</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Disclosure of illness to family and significant others/Reasons</strong></td>
<td>difsr</td>
<td>Disclosing diagnosis to the adolescents family and significant others/Reasons for disclosure.</td>
</tr>
<tr>
<td>• Disclosure from health professionals</td>
<td>dhp</td>
<td>Health professionals disclosing diagnosis to the adolescents.</td>
</tr>
<tr>
<td>• Reactions of adolescents, family and significant others to disclosure</td>
<td>rafsd</td>
<td>How the adolescents, their family and significant others respond or feel when they get to know about the diagnosis of the adolescents.</td>
</tr>
<tr>
<td>• Conditions for disclosure/Reasons for Non-disclosure</td>
<td>cdrn</td>
<td>What will make the adolescents disclose their diagnosis/why they will not disclose their diagnosis to family and significant others.</td>
</tr>
<tr>
<td>• Intentions of disclosure to a future partner</td>
<td>idfp</td>
<td>Plan to tell future partner about illness</td>
</tr>
<tr>
<td><strong>2. Anti-Retroviral Therapy (ART)</strong></td>
<td>art</td>
<td>Medications/treatment given to the adolescents as a result of having HIV.</td>
</tr>
<tr>
<td>• Perceptions of adolescents living with HIV concerning ART</td>
<td>pahca</td>
<td>What the adolescents think about the ART.</td>
</tr>
<tr>
<td>• The burden of ART/Other drugs for life</td>
<td>baodl</td>
<td>Difficulties/challenges faced by the adolescents as a result of the ART and other drugs</td>
</tr>
<tr>
<td>• Side-effects of ART and associated complaints</td>
<td>saac</td>
<td>Unfavourable outcomes/challenges faced by adolescents and other complaints about ART.</td>
</tr>
<tr>
<td>• Non-compliance/Compliance with ART/Consequences</td>
<td>ncac</td>
<td>Adolescents’ failure to take ART as indicated/results</td>
</tr>
<tr>
<td>THEMES AND SUB-THEMES</td>
<td>ABBREVIATIONS</td>
<td>MEANING/DESCRIPTION</td>
</tr>
<tr>
<td>-----------------------</td>
<td>---------------</td>
<td>---------------------</td>
</tr>
<tr>
<td>3. Care at the Hospital</td>
<td>ch</td>
<td>Receiving medical care at the hospital</td>
</tr>
<tr>
<td>• Signs and symptoms experienced by adolescents with HIV</td>
<td>ssah</td>
<td>Physiological manifestations of HIV in adolescents.</td>
</tr>
<tr>
<td>• Hospitalisation of adolescents with HIV</td>
<td>hah</td>
<td>Admissions as a result of HIV</td>
</tr>
<tr>
<td>• Follow-up/Appointment at the hospital</td>
<td>fah</td>
<td>Visits to the hospital by adolescents for review/seeking medical care.</td>
</tr>
<tr>
<td>• Quality of care at the hospital</td>
<td>qoc</td>
<td>Expression of satisfaction/dissatisfaction with care at the hospital.</td>
</tr>
<tr>
<td>4. Secrecy</td>
<td>sec</td>
<td>What the adolescents do not want family and significant others to know about themselves and their conditions.</td>
</tr>
<tr>
<td>• Hiding diagnosis, medications and symptoms from family, friends and significant others</td>
<td>hid</td>
<td>Adolescents hiding their diagnosis, medications and symptoms from significant others.</td>
</tr>
<tr>
<td>• Lying about diagnosis, medications and symptoms from family, friends and significant others</td>
<td>lie</td>
<td>Adolescents lying to hide their diagnosis, medications and symptoms from significant others.</td>
</tr>
<tr>
<td>THEMES AND SUB-THEMES</td>
<td>ABBREVIATIONS</td>
<td>MEANING/DESCRIPTION</td>
</tr>
<tr>
<td>-----------------------</td>
<td>---------------</td>
<td>---------------------</td>
</tr>
<tr>
<td><strong>5. Sources</strong> of Infection/Ramifications</td>
<td>sec</td>
<td>How the adolescents got infected with HIV and the outcomes.</td>
</tr>
<tr>
<td>• Source of Infection/consequences</td>
<td>sic</td>
<td>How the adolescents were infected with HIV and the effects.</td>
</tr>
<tr>
<td>• Loss of family members</td>
<td>loss</td>
<td>Loss of parents/siblings to HIV</td>
</tr>
<tr>
<td>• Reflections of adolescents with HIV</td>
<td>ref</td>
<td>Thoughts and fears of adolescents about the illness/death.</td>
</tr>
<tr>
<td><strong>6. Selected experiences of adolescents with HIV:</strong></td>
<td>ead</td>
<td>What adolescents have gone through as a result of having HIV.</td>
</tr>
<tr>
<td>• Education/school</td>
<td>edsch</td>
<td>What adolescents with HIV go through in school.</td>
</tr>
<tr>
<td>• Relationships</td>
<td>rela</td>
<td>What adolescents with HIV go through in their relationships.</td>
</tr>
<tr>
<td>• Financial</td>
<td>fin</td>
<td>Financial constraints encountered by adolescents with HIV.</td>
</tr>
<tr>
<td>THEMES AND SUB-THEMES</td>
<td>ABBREVIATIONS</td>
<td>MEANING/DESCRIPTION</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>---------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>7. Coping/Support</td>
<td>cop</td>
<td>Mechanisms put in place by the adolescents with HIV to deal with the illness/support from family, health professionals and significant others.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Relaxation/reducing stress/hobbies</td>
<td>rsh</td>
<td>Engagement in stress reducing activities.</td>
</tr>
<tr>
<td>• Religion</td>
<td>reli</td>
<td>Prayer to God offered by adolescents with HIV to help withstand the condition.</td>
</tr>
<tr>
<td>• Support</td>
<td>sup</td>
<td>Encouragement/support from family, health professionals and significant others.</td>
</tr>
<tr>
<td>8. Future prospects</td>
<td>fup</td>
<td>Thoughts of the adolescents with HIV concerning the future.</td>
</tr>
<tr>
<td>• Career plans</td>
<td>cap</td>
<td>What the adolescents with HIV plan concerning their jobs future.</td>
</tr>
<tr>
<td>• Plans of marriage</td>
<td>marr</td>
<td>What the adolescents with HIV plan concerning their marriage in future.</td>
</tr>
<tr>
<td>• Faith/hope/aspirations</td>
<td>hop</td>
<td>Expressions of faith and hope by the adolescents for a cure</td>
</tr>
<tr>
<td>• Future plans</td>
<td>fut</td>
<td>Long term plans of the adolescents with HIV</td>
</tr>
</tbody>
</table>