



# Understanding adolescents living with HIV in Accra, Ghana

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## ARTICLE INFO

### Keywords:

Adolescents  
Ghana  
HIV/AIDS  
Psychosocial  
Qualitative research  
Stigma

## ABSTRACT

This study explored the experiences of adolescents living with HIV (ALHIV) in Accra, Ghana. A descriptive study design with qualitative data collection and analysis methods were used. Thirty participants were purposively selected and data were collected through face-to-face in-depth interviews using a semi-structured interview guide. The interviews were audio-recorded, transcribed, and analyzed to identify emerging themes that addressed objectives of the study. The findings indicated that adolescents became aware of their HIV through family and non-family members, but were reluctant to disclose their HIV status to others due to varied reasons. Furthermore, it was found that the adolescents experienced stigma and also had conflicting views about clinic attendance and the antiretroviral therapy (ART). Evidence showed that some of the participants experienced financial challenges, which negatively affected their clinic attendance. In addition, participants reported they received support from healthcare providers, as well as their parents and guardians. The findings suggest the need for psychosocial interventions and financial assistance to adolescents living with HIV and their families.

## 1. Introduction

The prevalence of HIV/AIDS among adolescents and young people is an issue of ongoing concern. It has been established that adolescents and young people represent a growing share of people living with HIV worldwide (UNICEF, 2018). While declining among all other age groups, AIDS-related deaths among adolescents have increased over the past decade, and this could be attributed to a generation of perinatally-HIV infected children who are growing into adolescence (UNICEF, 2018). Besides, there is increased health care burden of perinatally-HIV infected adolescents who transition into adulthood (Machado, Galano, Succi, Vieira & Turato, 2016). Worldwide, adolescents continue to be unduly affected by HIV and as depicted in 2015, adolescents living with HIV (ALHIV) were approximately 1.8 million and out of this number, the majority (56%) were girls (UNAIDS, 2016; UNICEF, 2017). In 2016, 2.1 million people aged between 10 and 19 years, were living with HIV with 260,000 becoming infected with the virus (Slogrove & Sohn, 2018; UNAIDS, 2017a, 2017b). Between 2005 and 2016, the number of adolescents living with HIV rose by 30% (UNICEF, 2017).

Furthermore, in 2016, 55,000 adolescents between the ages of 10–19 died through causes that were linked to AIDS (UNICEF, 2017). AIDS is now the second leading cause of death among young people worldwide and the main cause of death among young people in Africa

with the majority of them living in sub-Saharan Africa (Kim et al., 2015; UNAIDS, 2015; UNICEF, 2011). In 2016, new HIV infections among adolescents in Africa was 73% (UNICEF, 2017). The situation is worrying, given that many African countries have youthful populations (UNAIDS, 2013), Ghana inclusive. It has been predicted that the number of 10 to 24-year-old Africans would increase to more than 750 million by 2060, which suggests that, even if current progress is sustained, new HIV infections among young people is expected to increase (UNICEF, 2016). Further, estimates indicate that between 2016 and 2030, as many as 740,000 more adolescents could become infected (UNICEF, 2016).

HIV infections among adolescents include *peri*-natal transmission (mother-to-child transmission), as well as through unprotected sex and sharing of contaminated instruments (Idele et al., 2014). ALHIV are vulnerable due to a myriad of biological, behavioral, social and structural reasons, which present some challenges when providing care for them (Kim et al., 2015; UNAIDS, 2011; UNICEF, 2011). Adolescence is a period of transition in physical, social and emotional domains and during this period, there is transition into adulthood and the development of self-identity, personal beliefs and standards, as well as an increase in risk taking behaviors and experimentation (Erikson, 1968; Guerra, Williamson, Lucas-Molina, 2012; Guerra and Bradshaw, 2008; Harter, 1998). The World Health Organization (2003) defines

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adolescence between 10 and 19 years of age, commencing at the onset of puberty. It has been argued that a definition of adolescence based exclusively on chronological age is unjustified and impractical and therefore a more functional definition based on the bio-psychosocial readiness of young people to enter adulthood would be more useful (Canadian Paediatric Society, 2003).

While the majority age of adolescence is 18 years in many countries, attaining this age does not ensure the possession of adult behavior (Machado, Galano, Succi, Maria Vieira, & Turato, 2016). Moreover, even though adolescence is an identifiable phase of life, its end is not always easily determined (Canadian Paediatric Society, 2003). It is important to note that adolescents are by no means an even population with similar needs that swing uniformly at the same age across the medical problem list (MacDonald, 2003). In view of the fact that adolescents are an arbitrarily set that consists of a chronological verge between adolescence and adulthood, those responsible for providing healthcare to adolescents must allow sufficient flexibility in the age span to incorporate different situations like a liberated minor or a young person with a chronic condition that could result in delayed development or protracted dependency (Canadian Paediatric Society, 2003). Accordingly, understanding the developmental pattern, though it may not be precisely the same for the adolescent, is imperative and as a result, it would be useful for healthcare providers to evaluate each adolescent's behavior as it applies to his or her health condition (Bell, 2006; Bell & Sawyer, 2010).

Although the changes that transpire during adolescence offer opportunities for positive growth experiences, they are associated with new susceptibilities (Machado et al., 2016). Thus, scholars have asserted that adolescent HIV/AIDS is a distinct epidemic that needs to be handled and managed separately from adult HIV (Naswa & Marfatia, 2010). The demands of the disease did not permit professionals who treated infected children to suspect that they could reach adolescence with its associated challenges (Machado et al., 2016). Many ALHIV have lost their HIV-infected parents leading to bereavement, interruption of emotional bonds, family rearrangements, stigma, (Ferrand et al., 2007) and in some cases, poverty and neglect (Chirimambowa, 2015; Suris, Michaud, & Viner, 2004). Also, the condition of ALHIV is worsened by the fact that while adjusting to changes; exploring life; and searching for identity and autonomy; they are compelled to deal with a highly stigmatized chronic illness that involves complex secrets about their families (Machado et al., 2016).

Generally, challenges reported by ALHIV, include disclosure to third parties, interpersonal relationships, treatment adherence and the psychological burden of living with a chronic illness that is associated with death, prejudice and social exclusion (Ankrah et al., 2016; Hosek, Harper, & Domanico, 2000; Machado et al., 2016). Also, poor abstract thinking and the development of autonomy may result in poor adherence to treatment (Suris et al., 2004). Furthermore, ALHIV experience abnormal growth that is associated with a different set of factors, such as malabsorption, inflammation, psychosocial factors, micro-nutrient deficiency, abnormal nitrogen balance, and impaired growth hormone secretion or action (Kim & Rutstein, 2010). Additionally, having a chronic illness in adolescence may result in poor physical growth, impaired sense of physical attractiveness, social isolation and educational or vocational difficulties (Chirimambowa, 2015; Suris et al., 2004). As these challenges are mostly persistent, the need to recognize and investigate them cannot be over emphasized (Li et al., 2010).

Furthermore, in terms of care, adolescents are often stuck between the snaps of pediatric and adult HIV care services (Lowenthal et al., 2014) and many ALHIV do not know their status. Generally, treatment adherence is lower and treatment failure rates are comparatively higher among ALHIV than in other age groups (UNAIDS, 2017a, 2017b). Some of the key obstacles are the psychosocial conditions in which adolescents live, the deep-rooted stigma surrounding HIV, adolescents' limited personal resources and dependence on caregivers, and the health

systems that are mostly unprepared to address the needs of ALHIV (Hudelson & Cluver, 2015). In Ghana for instance, care for people living with HIV is generally adult focused with more attention paid to the physical aspect of care, often leaving the psychosocial needs neglected. Also, even though there are antiretroviral therapy (ART) clinics in many parts of the country, in these facilities, care is provided mainly by clinicians with training in predominantly adult medicine.

In addition, while few health facilities run paediatric clinics for children until they are 18 years, unfortunately many of the children are transferred to adult clinics by age 12. This leaves a gap in care for the crucial period of adolescence, where there is lack of specialized clinics, especially for those with chronic conditions like HIV/AIDS. This study therefore explored the experiences of adolescents living with HIV/AIDS in Accra, Ghana. It is hoped that understanding the lives of the adolescents would help identify the idiosyncrasies, aspirations and challenges from their viewpoints (Machado et al., 2016). This is vital because the pathogenesis of adolescent HIV/AIDS comprise diverse factors over and above the disease and its causative organism, including physical, biological and psychological vulnerabilities, as well as situations that different groups of adolescents encounter (Naswa & Marfatia, 2010). Likewise, given the troubling news regarding current low rates of HIV diagnosis and treatment initiation among young people ages 15–24 with substantial challenges to epidemic control (Wong, Murray, Phelps, Vermund, & McCarragher, 2017), the importance of this study cannot be over emphasized.

## 2. Theoretical underpinnings

This study draws on Ewart (1991) Social Action Theory (SAT) as key aspects of the theory have been operationalized in HIV/AIDS-related research, in order to better reflect the ecosystems in which HIV-infected and affected individuals develop and live (Gore-Felton et al., 2005; Lightfoot, Rotheram-Borus, Milburn, & Swendeman, 2005; Traube, Holloway, & Smith, 2011). Also, it recognizes individual, social, and contextual factors that are influential against risk behavior (Ewart, 1991; Mellins et al., 2007; Remien et al., 2006; Simoni, Frick, & Haung, 2006; Traube et al., 2011). The theory suggests that health protection behaviors result from interaction among three domains: (a) responses to internal affective states that influence individuals' self-regulation processes, (b) self-regulation abilities of individuals, and (c) the larger environment context (Ewart, 1991; Gore-Felton et al., 2005).

### 2.1. Responses to internal affective states

Internal affective states relate to how better emotional adjustment to HIV/AIDS is linked with an active behavioral coping style (Gore-Felton et al., 2005; Namir, Wolcott, Fawzy, & Alumbaugh, 1987). In addition, better adjustment to HIV has been related to coping strategies, such as control, optimism, and interpersonal coping (Pakenham, Dadds, & Terry, 1994). Avoidance coping on the other hand, has been found to be associated with worse emotional adjustment to HIV/AIDS (Fleishman & Fogel, 1994; Nicholson & Long, 1990). Some stressors that characterize the lives of persons with HIV are parents and other family members; friends; financial difficulties; as well as mental health issues related to depression, suicide risk, substance abuse, and experiences of stigma, discrimination, violence, and sexual abuse (Gore-Felton et al., 2005).

### 2.2. Self-Regulation abilities of individuals

Given that stressors influence the lives of people living with HIV/AIDS, it is essential to regulate their internal affective states in order to reduce their engagement in transmission risk behaviors (Gore-Felton et al., 2005). Self-regulatory processes that reduce transmission risk behaviors, include (a) technical skills, (b) social skills, (c) interpersonal problem-solving skills and social cognitive beliefs and attitudes, (d)

reductions in substance use, (e) skills to deal with mental distress and (f) psychological processes related to sexual behavior (Gore-Felton et al., 2005).

### 2.3. The larger environmental context

Contextual factors that are associated with engaging in HIV transmission risk behaviors comprise relationship status, disclosure of HIV status, and offering sexual favors in exchange for things (Gore-Felton et al., 2005). Although it varies by gender, the context of risk behaviors is often connected to the disclosure status of HIV positive persons (Lee & Rotheram-Borus, 2002; Pizzi, 1992). Additionally, treatment is a key contextual factor that is related to health behaviors and outcomes of HIV-infected persons as they have different attitudes and feelings about HIV medications (Gore-Felton et al., 2005).

Additionally, using the social action theory, Lightfoot et al. (2005) noted that in adapting to their HIV status, young people (adolescents in this context) experience these phases: (a) establishment of an identity, (b) reflection of identity in social roles and (c) engagement in behavioral routines that endorse social roles within different settings and in certain behaviors, like reduction in the number of unprotected sexual risk acts (Lightfoot et al., 2005). These stages are crucial because during adolescence, roles are acquired and role-related skills, capabilities, and preferences are developed (Erikson, 1968). With regard to identity, as adolescents adjust to their HIV status, their social relationships with family members and romantic partners are changed. For example, news of an HIV status mostly leads to a role reversal between adolescents and their parents since parents usually need to be comforted by adolescents who disclose their HIV positive status. The theoretical perspectives were useful as they enabled the researchers to explore self-regulation processes, social relationships and health behaviors among HIV-positive adolescents.

## 3. Methodology

A qualitative research design was employed to explore the experiences of adolescents' living with HIV in Accra, Ghana. Given the sensitive nature of the research topic, the approach was deemed appropriate for the study. Qualitative research design allows researchers to explore sensitive, and complex issues, as well as understand human experiences and situations (Creswell & Plano Clark, 2011; Lewis & Ritchie, 2014). Also, it enabled the researchers to gain detailed information about the phenomenon based on the meanings attributed by those who experienced it (Creswell & Creswell, 2017; Denzin & Lincoln, 2018).

### 3.1. Study site

The study was carried out at the Adolescent HIV clinic of the Fevers Unit in the Korle-Bu Teaching Hospital (KBTH), the largest referral hospital in Ghana. This facility was chosen for the study because it is one of the two facilities in Ghana where specific services for adolescents with HIV are offered, and being the largest referral facility it had the appropriate population to sample from. The Fevers Unit is under the Department of Medicine and Therapeutics of the Korle-Bu Teaching Hospital. The unit is responsible for registration and management of all patients diagnosed with HIV, primarily in KBTH, as well as referrals from other health institutions in Ghana. The Unit started providing antiretroviral therapy in 2003 and runs three outpatient clinic days in a week. The Adolescent HIV clinic at Korle-Bu was started in 2012 and it is run by doctors and counselors at the Fevers Unit. The services provided are mostly flexible in order to improve attendance.

### 3.2. Participants and procedures

The study comprised 30 adolescents, including males and females.

The purposive sampling technique was utilized to recruit adolescents for the study. Purposive sampling enables researchers to select a sample based on the knowledge of the population, its elements, and the purpose of the study (Babbie, 2013). Adolescents living with HIV aged 12 to 19 years were included in the study. Younger adolescents (10–11 years) were excluded from the study because they were treated at the pediatric HIV clinic. Furthermore, adolescents who were in-patients at the Korle-Bu Teaching Hospital at the start of the study were excluded, as well as adolescents who resided outside Accra.

Participants were recruited by counselors at the Fevers Unit of the KBTH based on consent and willingness to participate in the study. The counselors were familiar to the adolescents and volunteered to assist with the recruitment process. They recruited adolescents who were willing to share their experiences regarding their HIV status. After the recruitment process, the researchers met the participants to schedule interview sessions convenient to them. All adolescents included in the study reported being aware of their HIV-status and receiving treatment at the Fevers Unit of KBTH. While it was assumed that the adolescents were infected at birth and had lived with the disease for as long as they could remember, it was possible few of them were infected through other means.

Data were collected through individual interviews by two researchers and two research assistants using a semi-structured interview guide developed by the researchers. This approach provided opportunity for the researchers to interact with the participants, who were able to express their views freely (Boyce & Neale, 2006). It was imperative to listen to the adolescents' voices as it enabled the researchers to better understand their experiences. Open-ended questions were used to explore participants' experiences regarding HIV. This allowed the researchers to probe participants' responses for clarification and deliberate on emerging issues in detail. Questions asked related to: disclosure; stigma and discrimination; healthcare services, as well as support and interpersonal relationships.

Each interview was conducted during adolescents' visit to the clinic for their regular appointment, took place in a private room, lasted between 60 and 90 min and was audio-recorded digitally with the participants' consent and approval. The interviews were conducted in English and other Ghanaian dialects (Twi and Ga) as all participants and researchers spoke either of these languages fluently. Each participant made a choice for language of preference. This approach limited the extent to which linguistic nuances were fluffed (Dako-Gyeke & Kodom, 2017). With regard to saturation, interviews were discontinued when the researchers observed no new information was elicited from subsequent interviews. Data saturation occurs when very little or no new phenomena emerges (Fontanella et al., 2011; Guest, Bunce, & Johnson, 2006).

### 3.3. Ethical considerations

The study received approval from the Institutional Review Board (IRB) of Korle-Bu Teaching Hospital. The purpose of the study was explained to each participant before the data collection commenced. Participants were informed about the benefits and possible risks of the study, and were further notified of their right to withdraw their participation at any point of the study. Informed consent, parental/guardian consent, and informed assent were obtained. Written consent for participation was obtained from parents and guardians of the adolescents and assent was obtained from the adolescents. The study procedure was clearly explained to parents and guardians who accompanied the adolescents to the clinic for their appointments prior to obtaining consent. Information was provided in clear simple terms, indicated the study procedure and level of participation required from the adolescents.

Parents and guardians were assured of confidentiality and privacy as all the study tools used did not have identifying information. For the parents and guardians who did not accompany their adolescents to the clinic for their appointments, the consent forms were sent to them

through the adolescents and those who had questions, concerns or both contacted the researchers for clarification before they completed and submitted the forms. Participation in the study was voluntary and confidentiality was ensured by concealing the identity of participants. Participants completed a short pre-interview demographic questionnaire. Upon completion of the interviews, participants were given snacks, money for lunch and reimbursement for travel. These items were approved and recommended by the IRB.

### 3.4. Data analysis

After the data collection, the audio recorder was replayed several times for the purpose of transcribing the data. Interviews carried out in Ghanaian languages were translated into English and some quotations were edited grammatically, ensuring preservation of the content. All identifying information regarding participants and the health facility were concealed and transcripts were saved with no personal identifiers. The data were analyzed at three major levels: initially, two researchers carefully and independently read and re-read the interview transcripts and applied descriptive codes (Lincoln & Guba, 1985; Miles & Huberman, 1994). This process enabled the researchers to reflect on the core content of the data and its meaning (Creswell, 2015; Miles, Huberman, & Saldaña, 2014).

At the next level, the researchers grouped similar codes into conceptual categories and each category had comparable characteristics (Miles & Huberman, 1994; Sargeant, 2012). The third stage was a higher-level of categorization and the researchers identified and summarized what they had learned with interpretive themes. The sets of codes, categories and themes independently developed were discussed and adjustments made through an iterative process until both researchers were in agreement. In order to ensure credibility of the findings of this study, the transcriptions were augmented with field notes taken by research assistants during data collection. Moreover, themes that were developed independently were interpreted and consensus was reached through discussions with academic colleagues who had professional and/or academic knowledge in the field (Lincoln & Guba, 1985).

## 4. Results

### 4.1. Demographic characteristics of participants

The sample consisted of 17 girls and 13 boys aged between 13 and 17 years. Table 1 describes the socio-demographic characteristics of adolescents who participated in this study. The next section is organized under the following themes: (a) disclosure of HIV status; (b) stigma, discrimination and HIV; (c) healthcare services; and (d) support and interpersonal relationships (Table 2).

### 4.2. Disclosure of HIV status

Adolescents' experiences with regard to how they became aware of their HIV status and whether they had shared or intend to share their status with others, were explored. It was found that disclosure was a major issue in the lives of HIV-positive adolescents. Both family and non-family members informed infected adolescents about their health condition:

*I remember the day my mother informed me of having contracted this sickness, it was a sad day for me. It is hard to understand because she is not alive to explain matters to me. I have a lot of questions demanding answers from her. It is not easy thinking about it as I did not acquire the virus myself, I became infected because my mother was infected and now she is dead. Sometimes, I fear that I would also die soon just like my mother. (Female, 17 years old).*

Some adolescents indicated that information concerning their HIV

**Table 1**  
Socio-demographic characteristics of adolescents.

Characteristics	Population n = 30
<i>Gender</i>	
Female	17
Male	13
<i>Age (years)</i>	
13	2
14	5
15	7
16	9
17	7
<i>Highest educational level (at the time of data collection)</i>	
Primary	2
Junior High School	14
Senior High School	11
Tertiary	2
Other	1
<i>Deceased parent(s)</i>	
Mother	9
Father	5
Both	5
<i>Marital status of parents</i>	
Married	8
Divorced	1
Widowed	13
Separated	3
<i>Clinic attendance since:</i>	
2002	1
2003	2
2004	3
2006	1
2007	2
2008	1
2010	3
2012	5
2013	3
2014	3
2015	1
2016	1
2017	4
<i>Payment of treatment by:</i>	
Mother	10
Father	4
Both parents	5
Aunt	3
Grandmother	3
Uncle	1
Foster Mother	1
Mother's Friend	1
Non-governmental organization	1
Self	1
<i>Lives with:</i>	
Mother	6
Father	4
Both parents	8
Grandmother	6
Foster mother	1
Aunt	3
Sibling	1
Mother's friend	1

status that was given to them, was not detailed enough:

*I live with my parents. Although they have not informed me, I suspect both or one of them is HIV positive. They revealed to me my HIV status, but they did not inform me how I got the virus. I have inquired about it many times, but they refused to provide detailed information. This bothers me a lot, but I cannot do anything about it because if I push further, they would presume that to be rudeness. I hope the truth will come out soon. (Male, 16 years old)*

Being a double orphan, this participant was informed about her HIV status by a non-family member:

**Table 2**  
Themes and sub-themes created based on analysis of the interviews.

Themes	Areas of focus
Disclosure of HIV status	Becoming aware of HIV status Informing others about HIV status / health condition
Stigma, discrimination and HIV	Enacted stigma Anticipated stigma
Healthcare Services	Clinic attendance Medication compliance
Support and Interpersonal Relationships	Interaction with health workers Interaction with family members

*A woman in my neighborhood told me I had HIV and she said I might have gotten it from one of my parents. Initially, I did not believe her. I was shocked and began to distant myself from my peers as I thought I could infect them with it. I am always sad and have so many questions, but I do not have anyone to help me with the answers. I cry often, bemoaning that I never got to know my parents, but sometimes I try to forget about it and focus on myself. (Male, 15 years old).*

In terms of revealing their HIV status to third parties, many of the adolescents indicated that they had kept their status a secret due to varied reasons, such as lack of information on how they acquired the virus:

*I do not think I would ever tell people, particularly my friends that I have HIV because nobody has explained to me how I acquired the virus. If I inform my friends and they want to know how I became infected, I cannot explain so it would be better to keep it a secret. Also, if one person gets to know, they would spread it. I do not want people to gossip about me or spread the news about my health status. (Female, 16 years old).*

Other adolescents did not disclose their HIV status in order to avoid being perceived as promiscuous:

*I will never tell anyone I am HIV positive. Many people, are ignorant of the various ways the virus could be transmitted and therefore think that infected individuals acquired the virus as a result of indiscriminate sex. It would be very embarrassing if others, especially my church members become aware of my HIV status. In case this happens, I would withdraw from church services. (Female, 15 years old).*

For fear of being stigmatized and discriminated against, some adolescents have not disclosed their HIV status:

*I do not think it is wise to let others know about my HIV status. If my friends get to know, they would shun me and make me feel lonely. Their parents and others would advise them to avoid me. Even, my parents have asked me not to inform anyone about it because it would adversely affect the reputation of our family. (Male, 17 years old).*

As explained by the ALHIV, disclosing their HIV status was a challenge given the possible negative consequences associated with it. Most often, stigma and discrimination compelled many of them to conceal information regarding their diagnosis.

#### 4.3. Stigma, discrimination and HIV/AIDS

Adolescents in this study revealed that they had experienced stigma and discrimination in different forms. While some of them reported being mistreated, others anticipated they would be stigmatized and discriminated against should they disclose their HIV status. Recounting how she was stigmatized and discriminated against, a participant noted:

*Yes, people have stigmatized and discriminated against me. Even at home, my siblings who are aware of my condition do not relate to me well compared to those who are not aware. They say a lot of negative things that suggest that I go about sleeping with several men. It is unfortunate*

*that because of ignorance about the disease, many people place blame on sexual contact. I do not know why people blame us, it is not our fault as we were born with the disease. (Female, 16 years old)*

Some adolescents indicated that people used their health condition as a basis to ridicule them:

*I live with my aunty who had a baby recently. She does not allow me to get closer to her or the baby. She said she does not want their blood to be contaminated. She only allows me to use disposable cups and does not allow me to cut my nails in the house. Also, some people in my neighborhood make fun of me because of my frequent visits to the hospital. I don't know how they got to know about my condition. (Male, 17 years old).*

Furthermore, other participants anticipated they would be stigmatized and discriminated against should they disclose their HIV status:

*I have vowed not to inform my friends of my HIV status because if they get to know, I will lose all of them. I am sure their parents will prevent them from going out with me. At school, anytime we had conversations about HIV-infected persons, my friends say nasty things about them. I cannot live my life in isolation so I have decided to keep my condition a secret. It is not easy, but I will try my best to keep it. (Female, 15 years old).*

In order to avoid blame and negative perceptions about them, some adolescents refused to disclose their HIV status:

*Apart from my mother, I lie to my siblings and friends anytime I go to the hospital for my check-up and medications. If they become aware of my condition, it would be a problem for me as they would blame me and probably shun me. I am compelled to keep it to myself. Anytime I think about my condition, I feel sad, especially knowing that I did not bring this upon myself, but got the virus from my parents. (Female, 17 years old).*

It is important to note that some adolescents reported they were not stigmatized or discriminated against, with the explanation that they had not disclosed to others or people were not aware of their health status:

*I have never experienced stigma or discrimination because no one is aware I have HIV. I am not treated differently, I go out freely and have normal relationship with others. I interact at will with my friends at school, neighborhood and church. Most of the time, I am happy, but sometimes I become worried when I think about my health condition. (Female, 13 years old).*

*I have not experienced stigma or discrimination because of HIV. Apart from my mother and sister, no one else that is close to me, knows about my condition. The two treat me very well. Everything is normal for me as I am able to go to school and engage myself in things other teenagers normally do. I hope people's attitudes and behavior would not change even if they became aware that I have HIV. (Male, 16 years old).*

Stigma and discrimination are major concerns for adolescents living with HIV because they are usually blamed and ridiculed. These could prevent them from accessing appropriate healthcare services with adverse impact on their health and wellbeing.

#### 4.4. Healthcare services

Clinic attendance and medication compliance are vital issues that are related to the health behavior and outcomes of HIV-infected persons. Adolescents included in this study, had different attitudes and feelings about clinic attendance:

*Attending clinic on regular basis does not come easily to me because it gives the impression that I have a dangerous sickness. For those of us in school, it is difficult because we have to wake up early on clinic days, to avoid being late for school. Sometimes, we are unable to get transport on time, we get tired, reach school late and miss some class work. I do not*



*find it convenient explaining my situation to my teacher and most often, I am punished for being late. Also, I get scared when I attend the clinic as I am not sure of the people I will meet there.* (Male, 15 years old).

Another participant who had difficulty visiting the clinic, but felt otherwise by the time she left the clinic asserted:

*I did not feel comfortable going to the Fevers Unit as I found it embarrassing. With my mother being jobless, it was challenging paying for my transportation to the clinic. My grandmother used to accompany me to the clinic and paid for the transportation, but now she is very old and does not accompany me anymore. Also, I did not like how the clinic was isolated from the main hospital. Once you enter the HIV clinic, people become suspicious. Initially, when I heard the name Fevers Unit, I thought it was a mental health facility, but after my visit, I was okay since everything was normal like other hospitals.* (Female, 16 years old).

According to other participants, visiting the hospital for treatment was not a problem as two participants, a male and a female, had these to say respectively: *"It doesn't bother me at all, I like visiting the Fevers Unit because the environment is very good. I like the location, as it is separated from the main hospital, we are kept out of the public view when we visit the place"* and *"I look forward to my hospital visits because I get the opportunity to receive medical treatment in order to improve upon my health. It is a good and clean place and things are done orderly"*.

With regard to antiretroviral therapy (ART), although some participants attested to the benefits of the medications, others had some concerns. In terms of the usefulness associated with taking the medications, two females noted: *"I feel healthy and good about myself because the HIV medication given at the Fevers Unit are helpful. I take my medicines consistently so that the virus will leave my body and my quality of life will improve"* and *"I do not have any problem taking my medicines regularly and obeying the rules of treatment. I hope that the medicines would cure and help me regain my strength and self-esteem."* In addition, two males revealed: *"I started taking the HIV medicines seriously and as a result, I stopped coughing. I was slim, but now, I have gained some weight and have realized that everything is alright and I am living a good life"* and *"I feel healthy because of the HIV medicines, it relieves me of pains. I want the virus to reduce in my body so I have to be serious with my medicines."*

Echoing her fears about taking HIV medications, a participant explained:

*I am always worried that I have to take HIV medication for life and they are expensive. My parents have been struggling financially to purchase my medications since childhood. Sometimes I do not take my medicines when I think about the fact that these medicines only help manage the condition, but do not cure. I feel it is time wasting taking these medicines. When people get to know that I take these medications, they will gossip about me. At school, my colleagues, especially the boys have asked many times about my regular taking of medicines. I told them I had a problem with my neck so a doctor gave me a pain killer to help reduce the pain.* (Female, 17 years old).

Another participant who was skeptical about taking HIV medications, recounted:

*The HIV medications are ineffective because they cannot cure the virus, but we are taking them daily. For some of us, we are orphans so it is difficult financing the purchase of the medicines and other basic things. I am sure herbal medicines will be able to cure the virus. I heard that some HIV infected people have been cured by traditional doctors and some pastors. I will explore that because I cannot live with the disease for life and continue taking medications that cannot cure the disease. I need a cure not treatment.* (Male, 16 years).

Undoubtedly, the adolescents living with HIV held beliefs, as well as had concerns about clinic attendance and antiretroviral treatment. These could have an impact on their engagement in care and therefore

suggests the need for social support from family and healthcare professionals in order to ensure their retention in care and adherence to antiretroviral treatment.

#### 4.5. Support and interpersonal relationships

As adolescents adjust to their HIV status, the support they receive and their relationship with people, particularly family members and healthcare professionals become crucial since they are likely to interact with them more or shy away from them. Commenting on the support he received from his family, a participant revealed:

*My parents and siblings are very caring. They ensure that I eat well and have enough medications to take regularly. My parents offer advice concerning my condition, which has made me strong emotionally. They provide money for my transportation anytime I attend clinic and sometimes accompany me to the Fevers Unit. The support I receive from my family has made me very confident and I appreciate it.* (Male, 13 years).

Another participant indicated that although her parents were financially constrained, they provided for her needs:

*My parents are committed and are very supportive. Although they are financially constrained they ensure that my siblings and I always have food, clothes and other basic needs. They also ensure that my medications are bought and they take good care of me whenever I am sick. They encourage me to take my education seriously and frequently check on me to take my medications. Anytime I forget to take my medicines before going to school, my mother brings them to me at school.* (Female, 14 years).

An adolescent who felt his mother mistreated him, explained:

*My mother is not supportive at all; she keeps expressing her disappointment in me and complains that I fall sick too often. I feel bad about it and it gives me the impression that she does not love me compared to my other siblings who do not have the disease. That hurts me and sometimes I become fed up with life. I wish I could live with someone else who would take good care of me.* (Male, 16 years).

In addition to providing medical care, the healthcare professionals offered assistance to adolescents in other ways. A participant described the cordial relationship that existed between them and healthcare professionals:

*The environment at the Fevers Unit is conducive. The doctors and nurses are good, caring and patient with us as if we are their own children. Each time I attend clinic, they treat me very well, specifically when I was on admission. Also, every December they organize a party for us and all the nurses, doctors, counsellors and pharmacist join us and we have lots of fun.* (Female, 14 years).

Commenting on the financial and emotional support they received from health care professionals, a participant had this to say:

*They are all caring and concerned about our wellbeing. Most often, the doctors give us money for food and transportation because sometimes our parents are unable to offer the needed funds. It is difficult getting money always to pay for our transportation, medication and even food. Occasionally, the nurses call by phone to check on me. Also, the counsellors encourage us often, especially when we are distressed.* (Male, 15 years).

Some adolescents reported they were mistreated by some healthcare professionals:

*Even though they know our condition, some of the nurses do not treat us well when we attend the clinic. They try to ignore us and find it difficult talking to us. Also, when we go to the pharmacy, the staff delay us unnecessarily, which is irritating because they do not treat other patients similarly.* (Female, 17 years).

It is important to understand the circumstances of adolescents living with HIV, particularly their challenges and the social supports they received from family members and health care professionals. In view of the fact that many children living with HIV are surviving into adolescence, issues regarding their social and psychological adjustment could hardly be overlooked. In this regard, ALHIV need to be supported accordingly.

## 5. Discussion of findings

This study explored experiences of adolescents living with HIV in Accra, Ghana. Our findings showed that disclosure was a key issue in the lives of the adolescents. Although through family and non-family members the adolescents became aware of their HIV status, they were reluctant to reveal such information to others, for different reasons (i.e., lack of information on how the virus was acquired; avoid being perceived as promiscuous, and fear of being stigmatized and discriminated against). It is however, unfair to perceive ALHIV as promiscuous as many of the adolescents included in this study acquired the HIV virus through *peri*-natal transmission. Also, some of the adolescents reported that the non-disclosure of their HIV status was as a result of parental/guardian advice. Usually, disclosure to third parties is among the challenges reported by ALHIV (Machado et al., 2016; Hosek et al., 2000). Disclosure of HIV status is crucial in adolescent populations, as it involves revelation to the infected child, as well as the adolescents themselves to others, such as family, friends, and members of their school and community (Ankrah et al., 2016; Maskew et al., 2016). In view of the fact that adolescents are emotionally vulnerable and how they would respond to their disease status could not be predicted, disclosure issues should be handled perceptively and patiently with the active involvement of health care providers and trusted family members (Henry-Reid & Martinez, 2008; Naswa & Marfatia, 2010).

The social action theory suggests that contextual factors that are associated with engaging in HIV risk behaviors, include disclosure of HIV status (Gore-Felton et al., 2005). Generally, adolescents are compelled to manage on their own with a disease that involves complex secrets (Machado et al., 2016). Fear and secrecy associated with HIV infection, could lead to stigmatization and discrimination against ALHIV, as found in this study. The adolescents revealed that they had experienced stigma and discrimination in diverse forms, such as being blamed and ridiculed by family members and friends. Furthermore, others refused to disclose their HIV status because they anticipated stigmatization and discrimination if their status became known by others. Whether it is experienced or anticipated, stigma impacts negatively on the lives of ALHIV because while adjusting to changes; exploring life; and searching for identity and autonomy, they are forced to cope with a highly stigmatized chronic condition (Ferrand et al., 2007; Machado et al., 2016). Experiencing a high level of stigma may result in psychological distress and lowered health among HIV- infected persons (Earnshaw & Chaudoir, 2009). HIV-related stigma undermines ART adherence through general and group-specific psychological processes (Katz et al., 2013).

In our study, evidence indicated ALHIV had different attitudes and feelings about healthcare services in terms of hospital attendance, HIV medications and relationship with healthcare professionals. While some adolescents felt comfortable attending HIV clinics at the Fevers Unit, others had challenges with the frequency of attendance and location of the facility. In view of the fact that some of the participants were still enrolled in school, attending clinic regularly was challenging since they had to juggle clinic visits and school attendance. Also, frequent clinic attendance was a problem due to financial constraints, as some adolescents, especially orphans and those from financially constrained households had difficulty paying for their transportation to the hospital. Battling a chronic disease like HIV amidst financial constraints could be challenging, mostly in situations where adolescents would have to worry about money when accessing healthcare services. One of the

stressors that characterize the lives of persons with HIV, according to the social action theory, is financial difficulties (Gore-Felton et al., 2005).

Financial challenges could lead to discontinuities in care, principally medication compliance since adolescents may not attend scheduled clinic appointments regularly. As noted by Kunutsor et al. (2010) and Mugavero et al. (2009), regular clinical attendance for medication refills and optimal adherence to ART are essential for successful clinical outcomes in HIV treatment as continuity of care is crucial to ensuring maximum benefits of ART. Treatment programs that require patients to attend clinic frequently or travel longer distances to receive necessary treatment increase the economic burden (involving transport costs) and time constraint that serve as barriers to HIV care adherence (Amuron et al., 2009; Geng et al., 2010; Ankrah et al., 2016; Maskew et al., 2016). With regard to medication, adolescents had differing views about the antiretroviral therapy. While some adolescents perceived ART as beneficial, others had concerns about dependency and stigma associated with the medications. Similarly, Farley et al. (2005) found that some HIV patients saw hope and psychological relief in treatment advances, but others were fearful and doubtful about the efficacy of ART.

The benefits of ART notwithstanding, some HIV patients despise the dependency, side effects, as well as the shame and stigma associated with being on HIV treatment (Ankrah et al., 2016; Gore-Felton, 2005). In addition, some adolescents reported financial constraint as an inhibiting factor to access their medication. Aside from the fact that ARVs are free in Ghana, not all patients find it easy to afford the cost associated with regular travels to the clinic for their medication. These adolescents are likely to run out of medication resulting in non-adherence to treatment. Furthermore, some adolescents who were skeptical about ART indicated their willingness to use herbal medicines as effective alternative treatment to the illness. This is disturbing in view of the fact that the efficacy of ART could be compromised if ALHIV combine ART with herbal medicines. Although people of all ages could use herbal medicines, adolescents may be more at risk because that is the stage in life where they develop self-identity, personal beliefs, and are more prone to risk taking and experimentation behaviors (Erikson, 1968; Guerra, Williamson, Lucas-Molina, 2012; Guerra and Bradshaw, 2008; Harter, 1998). Thus, the extent to which ALHIV could be at risk after experimenting different traditional and herbal medications for HIV treatment and or cure, cannot be overemphasized.

In Ghana, people resort to unorthodox medications and services (herbal preparations and spiritual incantations and invocations) provided by traditional and spiritual healers for many chronic health conditions, especially those that are not curable (Dako-Gyeke & Asumang, 2013). The use of herbal medicine, faith healing and other indigenous health resources for HIV/AIDS treatment is common in sub-Saharan African countries (Bodeker & Burford, 2007; Peltzer et al., 2011; Tamuno, 2011). While the pharmacology and toxicity of these herbs have not been assessed (Kloos, Damen, Kaba & Tadele, 2013), some HIV-infected persons, perceive traditional or herbal medicines to be familiar, trusted, and culturally suitable in sub-Saharan Africa (Bodeker & Burford, 2007; Peltzer et al., 2011; Kloos, Mariam, Kaba, & Tadele, 2013). Besides, a plethora of studies have reported that the use of traditional medicine by persons living with HIV was due to traditional beliefs in supernatural causes of HIV infection and the need to treat both physical and mental manifestations of the disease in order to restore social and spiritual health, shortage and high cost of ART and associated health services, as well as side effects of ART (Merten et al., 2010; Peltzer et al., 2011).

Provision of information by healthcare providers and other stakeholders, especially parents on the dangers associated with the use of traditional and herbal medications for HIV treatment and cure would be useful. This would help reduce the extent to which ALHIV may be exposed potentially to toxic herbal medicines that could result in drug interactions with adverse effects on their health. Moreover, apart from

few adolescents who reported otherwise, many of them indicated the existence of support from and good relationships with health care providers and family members. This is useful for their health and general well-being since many ALHIV have lost their parents due to AIDS, resulting in disruption in emotional bonding, family rearrangements, stigma, poverty and neglect (Chirimambowa, 2015; Ferrand et al., 2007; Suris et al., 2004). Adolescents in sub-Saharan Africa are among the most vulnerable to HIV and those who reside in households affected by AIDS are poor, socially disconnected, and many have been orphaned by one or both parents (Hallman, 2008). These individual, social, and contextual factors could influence risk behaviors among adolescents (Ewart, 1991; Mellins et al., 2007; Remien et al., 2006; Traube et al., 2011).

Moreover, it is important to address financial challenges among adolescents living with HIV, as poverty could compel some of them to engage in unsafe behaviors that would be detrimental to their health and that of others. Adolescents are more likely to engage in risky behaviors when they believe their life opportunities are restricted (White, 2002). This is particularly true for young females, who mostly have greater social, economic and health vulnerabilities, and less protective assets in their environments (Hallman, 2008). Further complicating the issue is the fact that prevalence of HIV is disproportionately higher in adolescent girls than in boys (Gregson et al., 2002). It would therefore be appropriate if interventions and programs that aim at addressing the needs and concerns of ALHIV take gender issues into consideration.

### 5.1. Strengths and weaknesses of the study

This study is valuable because adolescents living with HIV are prone to challenges, particularly stigma and discrimination, which could negatively affect their health and wellbeing. Even though support services may be available, accessing these services may be difficult for some ALHIV due to varied reasons. Thus, allowing HIV-positive adolescents to share their daily experiences served as a conduit in drawing attention to the plight of this vulnerable group. Also, the study could help offer support for emphasizing research in this vital area.

The above notwithstanding, a limitation to this study, which merit consideration is that the participants excluded adolescents living with HIV who did not access services at the Fevers Unit of the Korle-Bu Teaching Hospital. Hence, the findings may not be generalizable to the whole country. Another limitation is the likelihood of our population being biased as we might have collected data from adolescents who were motivated people with regular clinic attendance. Albeit the limitations, the findings revealed experiences of ALHIV included in this study, which could be applied to similar contexts provided there is some degree of similarity between the contexts (Lincoln & Guba, 1985).

## 6. Conclusions and implications

In conclusion, the findings of this study demonstrate the concerns and challenges ALHIV experience in relation to disclosure, adherence to treatment and stigmatization. Experiences of stigma, as well as the fear of being stigmatized in the future underpinned adolescents decision to conceal their HIV status and this had implications for clinic attendance and treatment. Any meaningful solution to HIV infection and AIDS-related deaths among adolescents must recognize and address non-disclosure and stigma as root causes of the problem. This suggests the need for provision of comprehensive psychosocial support for ALHIV. The role of social workers, as well as healthcare professionals is therefore crucial in helping adolescents and their families learn how to manage issues related to disclosure and stigma. This could serve as one of the pathways to ensuring high rates of HIV diagnosis and treatment initiation among adolescents and consequently enhance epidemic control.

Furthermore, adolescents living with HIV included in this study, had mixed feelings regarding clinic attendance and adherence to medication. Besides, of much concern was the finding that adolescents who

were skeptical about ART, were willing to use herbal and traditional medicines and services with the hope of HIV cure. Public education and awareness creation on the dangers associated with combining ART with herbal medications should be stepped-up since such practices could result in drug interactions and default in treatment. Moreover, poverty was identified as a barrier to treatment compliance. In order to reduce the financial burden of HIV-infected families, they could be encouraged to enroll in social protection programs, such as the Livelihood Empowerment Against Poverty (LEAP) and the National Health Insurance Scheme (NHIS). In addition, evidence showed that ALHIV received support from their parents, guardians and healthcare providers. This is beneficial and should be sustained as it would enhance their emotional adjustments and also help reduce the extent to which ALHIV would engage in risky behaviors.

## Acknowledgements

This project was made possible with financial support from World Health Organization (WHO). Special thanks to the Strengthening Capacity for Implementation Research (SCapIR) Initiative through the University of Ghana's School of Public Health Regional Training Centre that managed the call for proposals and issued small grants for research. Furthermore, our appreciation goes to adolescents, doctors, nurses, counsellors and pharmacists who participated in the study.

## Appendix A. Supplementary material

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.childyouth.2019.104590>.

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