

# Lived Experiences of Adolescents with HIV in Rwanda: A Phenomenology Study

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## Abstract

### Background

HIV is a chronic disease with a potentially negative impact on quality of life. Globally, adolescents with HIV (AWH) face incredible challenges related to their growth, social interactions, and well-being. The experiences and choices of AWH in Rwanda are poorly known.

### Objective

The current study explored the lived experiences of AWH in Rwanda using an interpretive phenomenological approach.

### Methods

A purposive and snowball sampling was used to recruit twenty AWH from five health centers. A semi-structured interview guide was used to conduct in-depth interviews from April to August 2022. All interviews were recorded, and field notes were taken. The recorded interviews were transcribed verbatim, translated in English, and analyzed using Interpretative phenomenological analysis (IPA).

### Results

Three main themes and nine subthemes emerged from data: burden of HIV (existential crisis, experiences with stigma, keep it a secret), owning my story (awareness of having HIV, making decisions) and successful living with HIV (features of successful living, continuum of self-acceptance, behavioural impact, social interaction).

### Conclusion

The AWH face challenges related to HIV condition and develop strategies to overcome challenges that hinder their well-being. Results provide valuable insights that inform targeted interventions and support programs, ultimately promoting the well-being of AWH.

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**Keywords:** adolescent, HIV, lived experience, phenomenology, Rwanda

## Introduction

The HIV prevalence among adolescents is a major public health problem, particularly in high HIV prevalence areas. Although there is a decrease of new HIV infections globally due to the scale up of antiretroviral therapy (ART), HIV remains a global public health concern.[1–3] At the end of 2022, global HIV statistics indicated that 1.5 million children were living with HIV worldwide.[4] Globally, children who acquired HIV vertically experience challenges related to functional autonomy and adherence to antiretroviral (ART) medications.[5] Adolescents with HIV (AWH) have an elevated mental and behavioural health burden most especially in low- and middle-income countries (LMIC) affecting HIV prevention, care, and treatment.[6]

The 95-95-95 targets from the UNAIDS was initiated as a way of planning to provide better support to people with HIV (PWH) and describe progress related to the HIV continuum.[7] These targets aimed that 95% of PWH globally will know their HIV status; 95% of people who were diagnosed to have HIV will be on antiretroviral therapy (ART); and 95% of people on ART will have a suppressed viral load. The objective of this strategy was to establish adolescent-friendly services at already-existing health facilities in order to raise the proportion of adolescents who are aware of their HIV status, adhere to treatment, and have a lower viral load. The AWH would receive antiretroviral therapy in a way that is approachable to them, and they would receive support for any queries or worries they may have regarding their course of treatment.[8]

In Sub-Saharan Africa, there is a progress in the reduction of new HIV infections among children compared to late 1980s. Although several epidemic and economic measures that were implemented in many countries have been shown to be effective preventive measures that reduced the number of new HIV infections, the prevention of new HIV infections has advanced far more slowly.

Since 2000, programs designed to stop HIV from being transmitted during pregnancy, childbirth, and breastfeeding have prevented an estimated 3.4 million infections.[9] The primary mode of HIV infection in sub-Saharan Africa is heterosexual sex, contributing to a significant epidemic in the region. Through vertical transmission from mother to child during pregnancy, childbirth, or breastfeeding, this form of transmission also causes an epidemic in children in many parts of Africa.[10] The adolescents, especially girls, are more vulnerable to HIV infection due to several circumstances. They often engage in frequent relationships with elderly partners who can have a higher HIV prevalence. In addition, their risks are increased by inadequate condom use and limited access to comprehensive sexual and reproductive health services.[11–14] Despite the advancements of HIV prevention and care in sub-Saharan Africa, AIDS continued to be the biggest cause of death among the general population in 2022, taking one life every minute.[9]

There have been considerable advancements in HIV prevention, testing, and care in Rwanda. HIV screening is done in healthcare facilities and other locations that have been recognized as hotspots for new HIV infections or with a history of high rates of recent infections. Over the past 25 years, the national HIV and AIDS control program in Rwanda has been successful in decreasing the prevalence of HIV in the general population.[1] In addition, Rwanda adopted the WHO strategy of 95-95-95, and it is among five countries in Africa that achieved these targets in general population by the year 2022.[9] However, the annual report of the Rwanda Ministry of Health in 2023 indicates that adolescents, especially girls, are key populations requiring more investments to reduce new HIV infections.[15] The male AWH aged 15 to 19 years is the first age group with less adherence to antiretroviral therapy (90%) and more cases (10%) that were lost for follow up.[15] Despite the tremendous viral load suppression among the general population in Rwanda,

the viral load suppression among AWH ranges from 66% to 74%.[15]

The AWH is a group that includes people who acquired HIV vertically or horizontally. In Rwanda, vertical transmission is the most common way that children get HIV, and it occurs during pregnancy, during childbirth, or through breastfeeding. However, horizontal transmission is associated with sexual behaviours, receiving contaminated blood products with HIV, and using contaminated needles or syringes.[16] Most of the research on AWH in Rwanda focuses on their clinical and mental health outcomes, paying little attention to their lived experiences of AWH. Speaking to the needs of AWH, research on adolescent HIV experiences is still moving at a slow pace today. To fill these research gaps, guide policy, and enhance adolescent outcomes; innovative and focused solutions based on solid evidence are thus required.[8] This is why conducting a study on AWH in Rwanda and exploring their lived experiences will be important in generating the necessary knowledge and potential solutions to help develop adolescent-friendly policies that consider a holistic approach to healthcare, considering the social, psychological, and biological aspects of health.[17]

## Methods

### Study design and setting

This study used an interpretive phenomenological approach to explore the lived experiences of adolescents with HIV in Rwanda. Twenty (20) participants were recruited from 5 different health centers in 3 districts of Kigali city, the capital of Rwanda that has both urban and rural health centers. Health centers were chosen based on their different geographical locations and the number of AWH they registered. Nine (9) were recruited from two health centers in urban areas, nine (9) from two semi-urban health centers, and two (2) were from one rural health center in Kigali city. In Rwanda, health centers are the main treatment facilities for people with HIV and care is given by age groups

to facilitate the educational sessions provided by healthcare providers. Monthly or quarterly appointments to obtain medications are provided to adolescents based on their level of adherence to ART. Purposive and snowball sampling approaches were employed to select participants of this study. [18] This sampling method was utilized to recruit a heterogeneous sample based on living conditions (living alone or in a family, enrolled in a school or not, and being a peer educator or not), adherence to medications, age, gender, geographic location (urban, rural). All participants spoke Kinyarwanda, the native language.

To participate in the study, adolescents with HIV needed to (a) be between the age of 15 and 19 years; (b) have been diagnosed with HIV and registered in an ART service of the health center; (c) know their HIV status, and (d) voluntarily agree to participate in the study.

### Data Collection and Procedures

At each of the five health centers, the head of the health center and nurses in charge of ART services were contacted to discuss the purpose and methodology of the study. At each site, a register of all AWH that get care from that selected health center was consulted allowing purposive selection of key participants for the study. Thereafter, the nurse in charge of ART service at each health center called identified AWH to introduce the study and determine willingness to participate. Among those AWH interested in participating, the nurse in charge helped schedule individual interviews.

On the day of the interview, after informed consent/assent procedures were completed, the researcher established rapport with participants prior to the start of interview. Then, participants were individually interviewed using a pre-established interview guide. The researcher used an interview guide that was developed by the entire research team prior to its use and probing was done to obtain rich data. The interview guide was used to facilitate flow of

the interview and to engage participants to openly express their lived experiences with HIV. The interview guide included open-ended guiding questions about when, how, where, and by whom the adolescent learned of his HIV status, as well as their immediate and long-term reactions to learning she/he had HIV. Furthermore, the interview guide delved into the adolescent's experience of living with HIV, as well as questions concerning developing aspirations.

Finally, the final questions focused on understanding the concept of successful living in general, its characteristics, and how this concept is applied to AWH. At the end of each interview, each participant was asked to recommend an adolescent that he considers living successfully with HIV, those adhering well or not to ART and treatment, and who would possibly be agreeable to being contacted by the researcher.

During the interviews, the researcher used a conversational tone and employed active listening to understand experiences of participants and regularly checked for better understanding with participants by using probes.[19] Probing referred to context-specific interview questions to fully comprehend participants' experiences to capture everyone's specific condition. This iterative adaptation of data collection came up with rich data where different categories emerged.

Data saturation was continually assessed by the researcher during data collection. With the fifteenth interview, data saturation was achieved. However, five additional interviews were done to increase the credibility of the findings and validate emerging themes. All interviews were conducted in Kinyarwanda and audio recorded. Interviews were conducted in one of the rooms of the ART services at each health center and they lasted between 21 to 50 minutes in length (mean = 37 minutes).

### **Data Management and Analysis**

At the end of data collection, recorded individual interviews and written memos were saved on a computer hard drive.

Collected data was immediately transcribed verbatim in Kinyarwanda and translated in English by the primary researcher for analysis. Then, back translation was done by additional two researchers to eliminate any possible errors and ensure contextual and linguistic equivalence of the English transcript. In addition, personal or identifying information names and all possible identifiers were removed from the transcripts prior to being imported into MAXQDA 2022 qualitative software [20] for coding and analysis.

The Interpretative Phenomenological Analysis approach [2] guided data analysis in identification of codes and allowing in depth exploration of the lived experiences of adolescents with HIV. Interpretive phenomenology allows the researcher to better understand shared experiences and differences among study participants by categorizing data and formulating appropriate themes and subthemes. [19] Independent coding was done by two researchers from the research team and agreed on the coding strategy through discussion and consensus. They identified potential patterns from interviews using the same translated 20 transcripts, and a priori developed codebook that was approved by the research team prior to conducting interviews with participants and formulated themes and subthemes through inductive coding.

After verifying codes occurrence, a Coefficient Cohen's Kappa ( $k$ ) for exact segment matches of 0.86 ( $k=0.86$ ) was calculated indicating a high interrater reliability. Thereafter, the two independent coders met with the full research team in regular weekly meetings to discuss identified themes and subthemes. The use of pseudonyms for each participant in the study was done to preserve the participants' privacy which is a standard method for de-identifying data when publishing qualitative results.[21]



**Ethical Procedures**

Data collection was conducted between April and August 2022. Prior to study implementation, ethical approval was obtained from the Institutional Review Board of the University of Rwanda College of Medicine and Health Sciences (N° 047/CMHS IRB/2022), an ethical approval from Rwanda National Ethics Committee (No.107/RNEC/2022), and the collaboration letter from Rwanda Biomedical Center (Ref. N° 5534/RBC/2022). Written informed consent was obtained from participants aged 18 or 19 years while assent and informed consent were obtained from study participants aged 15-17 years and their parent/guardian. The AWH were compensated 2000 Rwandan Francs (equivalent to \$1.65USD) to assist with transportation expenses associated with travel to and from the health center for the interview.

**Rigour**

The four criteria for trustworthiness as set by Lincoln and Guba were used to validate the research findings of this study: credibility, dependability, confirmability, and transferability.[22] To ensure the credibility of findings and coding, there was member checks to validate interview findings by interviewing 5 new participants aged 15-19 years after saturation was identified. This was to confirm if the collected information reflects to participants’ insights and if they are robust. [23]

To ensure the dependability of the data, an heterogenous sample was collected through purposive and snowball sampling techniques and was engaged with them to understand the lived experiences of AWH through in-depth interviews until data saturation was achieved. To ensure the confirmability of the data, all authors were engaged in designing the study and participated in analysis and team discussions to facilitate agreement with study findings. To ensure the transferability of data, it was established by providing a detailed description of the topic, participants characteristics, data collection and analysis process, and results. For reflexivity, researchers prevented any bias during data collection, and analysis process by considering status and position as well as attitudes and beliefs about HIV.

**Results**

**Participants characteristics**

A total of 20 participants were recruited and interviewed in this study (n=10 girls; n=10 boys). The mean age of participants was 18 years, majority of participants were aged between 18 and 19 years (n=13, 65%) and 90% (n=18) of participants had acquired HIV through vertical transmission. The largest portion of participants (n=11, 55%) was enrolled in secondary school. The majority (83%) of participants reported to have had undetectable viral load on their last viral load test result. Demographic characteristics of participants are presented in Table 1.

**Table 1. Sociodemographic characteristics of participants**

Sociodemographic characteristics	Full sample (N = 20)		Girls (n=10)		Boys (n=10)	
	n	%	n	%	n	%
<b>Age</b>						
15-17 years	7	35	3	30	4	40
18-19 years	13	65	7	70	6	60
(Mean, SD)	(18, 1.5)		(18, 1.4)		(18, 1.5)	
<b>Level of Education</b>						
Primary	3	15	2	20	1	10
Secondary	11	55	3	30	8	80
Stopped studies	6	30	5	50	1	10
<b>Visited Health center</b>						
Rural	2	10	1	10	1	10
Urban	9	45	4	40	5	50
Semi-Urban	9	45	5	50	4	40

**Key:** SD, Standard deviation

**Table 1. Continued**

Sociodemographic characteristics	Full sample (N = 20)		Girls (n=10)		Boys (n=10)	
	n	%	n	%	n	%
<b>Location of Health centers</b>						
Near	10	50	5	50	5	50
Far	10	50	5	50	5	50
<b>HIV transmission</b>						
Vertical	18	90	8	80	10	100
Horizontal	2	10	2	20	0	0
<b>Viral load results</b>						
Decreased viral load	10	50	3	30	7	70
Not decreased viral load	2	10	2	20	0	0
No results	4	20	2	20	2	20
Not tested	4	20	3	30	1	10
<b>Age at disclosure</b>						
Birth to 9 years	5	25	3	30	2	20
10 to 14 years	10	50	4	40	6	60
15 to 19 years	5	25	3	30	2	20
<b>Duration on ART</b>						
<5 years	2	10	2	20	0	0
5 to 10 years	3	15	2	20	1	10
11 to 15 years	0	0	0	0	0	0
16 to 19 years	15	75	6	60	9	90

**Emerging Themes from Qualitative Interviews**

**Burden of HIV**

The burden of HIV was the first theme to emerge (please refer to Table 2). Participants described their experiences of having HIV and the burden caused by HIV before they knew the diagnosis, immediately after the diagnosis, and subsequently on daily life. Particularly, after learning of their diagnosis and in the daily life, living with HIV led them to lose hope, experience stigma, and make the decision to keep their HIV diagnosis a “secret”. This experience has manifested in existential crisis, experiences with stigma, and keeping it a secret.

**Table 2. Themes and subthemes**

Themes	Sub-themes
Burden of HIV	Existential crisis
	Experiences with Stigma
	Keep it a secret
Owning my story	Awareness of having HIV
	Making decisions
Successful living	Features of successful living
	Continuum of self-acceptance
	Behavioural impact
	Social interaction

**Existential Crisis**

For many of the adolescents, a diagnosis of HIV made them feel useless in the society and lose hope for the future. They felt threatened, frustrated, sad, and without having value. A participant recalled the experience by stating, “...I was too sad having many questions in me...” (Participant 9, a 16-year-old boy, semi-urban, vertically infected). Another participant from the rural area shared their reaction immediately after learning their HIV status, stating,

*After testing positive for HIV, I immediately experienced abrupt shock by that result and was admitted in the observation room at the health center. I was admitted until the evening when I recovered and decided to go back home... It was difficult to hear a positive HIV result.* (Participant 2, a 19-year-old girl, rural, horizontally infected)

Many participants described their lived experience as “not having real health”. They are worried about the severity of the disease which increase their level of stress. A participant from an urban area stated,

*You see, we do not have the same quality of life like others. Our immune system is not the same as those free from the virus. Even if you may be on antiretroviral therapy but you can't be the same as others... I think that it would be good if I can give birth for children free from HIV instead of filling the world with this virus. (Participant 16, an 18-year-old boy, urban, vertically infected at birth)*

### **Experiences with Stigma**

Participants also reported their experiences with stigma. Some participants faced stigma, others have adopted strategies that helped them to prevent all kinds of stigma mainly the enacted stigma (as being discriminated by others),[21] perceived (perceptions of stigmatizing attitudes from the community),[24] anticipated (expectations for possible mistreatment by others if the HIV status is disclosed),[21] and internalized (having feelings associated with HIV assimilated into self).[24] A participant from urban area also stated, "We are used to getting insulted by neighbors sometimes, saying that we are fat because of pills of HIV" (Participant 13, an 18-year-old girl, urban, vertically infected at birth). Another participant from semi-urban area stated,

*When I went to the District Hospital to get medications, I met a classmate who came with her mother. Her mother was the one on ART medications, but the classmate had no HIV. Arriving to the school, she told everyone that I have HIV and that I am on ART medications. She always mobilized others to look at me as a person with HIV. I used to pass near people and notice that they are talking about me... Then, I decided to drop out from school. (Participant 10, a 19-year-old girl, semi-urban, vertically infected at birth)*

Another participant from semi-urban area stated,

*I can't hesitate taking medications, as I know how important they are... I prefer coming to the health center late at around 08:30 AM or 09:00AM targeting when people will be few at the health center and nobody could see me when coming to*

*take medications (antiretroviral therapy). (Participant 4, an 18-year-old boy, semi-urban, vertically infected at birth)*

### **Keep it a secret**

Participants keep their HIV status confidential as a mechanism to prevent stigma and maintain control. They report to have been told by their healthcare providers to keep confidential their HIV status, "I can't disclose because we were told by healthcare providers to keep it as a secret. My siblings do not know my HIV status" (Participant 3, a 15-year-old girl, semi-urban, vertically infected at birth). They also add that HIV is their own problem, not to be known by any other person, "This is my own problem, I must keep it as a secret. Disclosing your HIV status is like being talkative because people you disclose to are not your healthcare providers" (Participant 2, a 19-year-old girl, rural, horizontally infected).

Participants do not disclose their HIV status believing it is the best option for not exposing their health and harming their future. They believe this is necessary to increase their relationship with others and build happy families. To fear risks associated with disclosure, a participant from rural area stated, "I can't disclose HIV status because if I disclose, none will any longer accept to play with me" (Participant 1, a 15-year-old boy, rural, vertically infected at birth). Another participant from the rural area shared her experience and plan:

*Disclosing HIV status is spoiling the information that would be kept confidential. People discriminate [against] you; they wonder why you divulge the HIV status while it is not necessary. I decided to keep it a secret in my heart as it is my own problem, and I prefer discussing on other general issues. (Participant 2, a 19-year-old girl, rural, horizontally infected)*

### **Owning my story**

Owning my story was the second theme in this study (please refer to Table 2). Participants believe to have a single story and being the master of what they go through. They get to know their HIV in different ways and decide how to shape their health.



Participants stated how they knew their HIV status; some were severely sick and were told their HIV status at the health center, others grew up being on medications and were told by health care providers or parents or guardians about their HIV status later in life, while there are participants who had sexual risk behaviours and got HIV. Despite the way everyone has got HIV, they make decisions on their health for wellbeing.

### **Awareness of having HIV**

Ways of knowing HIV differ among participants. According to participants' experiences, there is no single way to know HIV status and there is no specific age. It depends to the context by which participants came to know their HIV status. A participant from semi-urban area stated the way she knew that she had got HIV, "I did not react negatively after being told my HIV status because I already knew it, my mother had told me before." (Participant 3, a 15-year-old girl, semi-urban, vertically infected at birth). Many participants knew their HIV status following their attendance to health centers to get medications:

*As we used to go to the health center to get medications, my mum eventually explained it to me and explained that we came here to get medications from this health center. She told me that I have opportunistic infections and requested me not to blame her. As an adult person, she eventually explained what happened.* (Participant 5, a 17-year-old boy, semi-urban, vertically infected at birth)

Another participant from rural area stated, "I was told my HIV diagnosis to be positive when we were here at the health center. The nurse tested my viral load and told me that I have HIV" (Participant 1, a 15-year-old boy, rural, vertically infected at birth). However, some participants reported not to have been told their HIV status in time but took longer for them to know their diagnosis as the nurse and parents were not open. Some participants knew their HIV status because they had opportunistic infections and visited the health center to get care. By visiting, they were told to have HIV. A participant from urban area stated:

*I used to get frequent illnesses when I was 11 years old, and my elder sister asked me to go with her somewhere. She took me to the health center, they took blood sample, and she asked me to wait for her a while. Then, we were called together in the consultation where they told both of us that I Have HIV. We then sat and discussed how I have got HIV... (Participant 13, an 18-year-old girl, urban, vertically infected at birth)*

### **Making decisions**

It was participants' own choices to make decisions related to their health. Decisions to take medications for improving participants' health status were based on different circumstances. Giving value to medications was the most cited reason for adherence,

*I can't skip a night without taking medications. Life becomes worse when you do not take medications. Your immune system suppresses, and it takes time for antibodies to get back to normal. My life has changed when I started taking medications for HIV. Since 2019, I take medications regularly, and I only experience simple flu and cold symptoms. I was prone to diseases before taking medications for HIV where I should consult the health center two times a week being severely sick but now, I am free from those diseases.* (Participant 2, a 19-year-old girl, rural, horizontally infected)

A participant from the rural area stated, "I was told that I will not suffer from HIV related complications if I take medications well. I can live well with HIV like living with other health conditions" (Participant 1, a 15-year-old boy, rural, vertically infected at birth).

Another participant from semi-urban area stated, "I know what to do to keep me healthy, just taking my medications well. The HIV is not a problem when you take your medications" (Participant 6, a 19-year-old girl, semi-urban, horizontally infected). Support groups were determined as the right places where adolescents meet, feel relieved and be encouraged on taking medications:



*According to where I live, there are some health centers where you can take medications but without other services like support groups. I can suggest that support groups be available in all health centers they help a lot in encouraging adolescents to come for medications, for my side it allows me not to be alone. I meet friends with same problems as mine and I know that the problem is not for me alone, but it is common. (Participant 6, a 19-year-old girl, semi-urban, horizontally infected)*

### **Successful living**

Successful living is a third theme that emerged from data (please refer to table 2). Participants explained how they understand the concept of successful living and if they live successfully with HIV. As a complex theme, participants stated features of successful living, continuum of self-acceptance, behavioural impact, and social interaction.

### **Features of successful living**

Participants defined successful living of adolescents with HIV as a concept that show their wellness. Some participants indicated that successful living of adolescents with HIV refers to psychosocial wellbeing:

*I consider successful living as when a person is living in harmony with others without any problem, having no doubts and has accepted her/himself. I found that my friend has self-acceptance because we use to have conversations and he does not have any problem, he takes medications properly, no frequent illness. I have accepted myself and live in harmony with others. (Participant 4, an 18-year-old boy, semi-urban, vertically infected at birth)*

Other participants viewed successful living of adolescents with HIV as a general behaviour of interacting with others and taking medications as prescribed, not fearing to attend important activities due to stigma, presenting happiness and accepted social behaviours:

*I think I live successfully with HIV because I go to school, I play with schoolmates, I am happy all the time and I laugh for some time. An adolescent living successfully with*

*HIV should be adhering to antiretroviral medications, should be happy, should play with others, take a balanced diet and should help his parents. I have all those characteristics for an adolescent living successfully with HIV that I mentioned. I cannot disclose that I have HIV. (Participant 1, a 15-year-old boy, rural, vertically infected at birth)*

In addition, praying to God was found as one of practices that should be presented by adolescents who live successfully with HIV. They should have healthy behaviours, adhere to medications as prescribed, be happy, have hope for the future, and have self-acceptance.

*An adolescent who successfully lives with HIV should be careful by not transmitting HIV to others, taking medications properly, and eating balanced diet. He must also be praying because praying is helpful. Whatever religion you are part of, when you pray God, you understand that the condition you have is not due to hatred from God. You should never be hopeless because some loose hope due to taking medications every day. You should never be discouraged or lose hope. But praying and being careful are very helpful... (Participant 16, an 18-year-old boy, urban, vertically infected at birth)*

A few of participants added that chatting with everyone, sharing HIV status to those who are close and may not discriminate you, and working for self-development would be features of successful living:

*A person lives successfully with HIV when she or he copes well with HIV ... and should not have depression... She does not present any problem and you find her sharing feelings with everyone being happy... She has positive social behaviours... usually provides the testimony about her HIV status with us who have the same HIV status. She urges about having good legacy, not having emotions that may interfere with daily activities or feeling guilty or isolated. She talks about her interesting personal development that came after self-acceptance, and the way HIV did not stop her daily living activities. (Participant 2, a 19-year-old girl, rural, horizontally infected)*

### Continuum of self-acceptance

The concept of self-acceptance was raised by almost all participants indicating that it is the main characteristic aimed by every participant. They further indicated that it is the main characteristic of people who live successfully with HIV. A participant from urban area stated,

*The AWH present self-acceptance when they live successfully with HIV. They show an advanced understanding that any problem they are having whether simple or complicated one, are not the only ones with it, ... they present good health and demonstrate happiness and socially accommodative behaviours without loneliness. (Participant 18, an 18-year-old boy, urban, vertically infected)*

Participants develop self-acceptance progressively and from different stimuli. Some become religious persons after developing self-acceptance and everyone considers HIV to be a usual infection like others:

*When a nurse told me my HIV status, I thought that life was over. I did not have hope for life, and I thought it was just over. She (nurse) just tried to reassure me as a health care provider, but I left the health center without accepting it. Later when my dad explained to me about HIV and when I continued praying, I got another way of viewing HIV condition. I then accepted the situation. (Participant 1, a 15-year-old boy, rural, vertically infected)*

### Behavioural impact

Successful living is a complex phenomenon interpreted differently. Some of the participants considered keeping HIV a secret to be the primordial way of successful living with HIV. This may lead to sexual risk behaviours, pertaining not to disclose to the partner and having safer sexual contact:

*... when she can't control herself, you can do it [have sex] to avoid that she can go everywhere talking about you, as being sexual impotent. What if I am provoked for example by a girlfriend? It is hard to abstain myself. When I am going home from support groups and I meet her (girlfriend) during the night,*

*I can control myself, but she may not. To avoid that she can go talking about me to her friends, I do it [have sex] even if I went without carrying it (having condom) as long as it is in a private place. (Participant 7, a 19-year-old boy, semi-urban, vertically infected at birth)*

In addition, being collaborative and live peacefully with all should be a guiding principle of participants that live successfully with HIV. One participant from semi-urban area stated, "We should provide peace and get peace from others, take medications properly, get time for rest, eat food rich in nutrients and get entertained" (Participant 6, a 19-year-old girl, semi-urban, horizontally infected). Another participant from urban area stated, "We should accept HIV condition and have discipline" (Participant 15, a 16-year-old girl, urban, vertically infected at birth). However, unusual behaviours are sometimes presented by participants when they remember that they have HIV, an untreatable infection. One participant from urban area stated:

*I sometimes live a happy life with my parents without any problem, but I sometimes change the mood when I think about my problem (having HIV). In that case, I just change the way I behave and once they ask me why I changed, I do remind them that they are the source of my HIV and look at them! (Participant 15, a 16-year-old girl, urban, vertically infected at birth)*

### Social interaction

The successful living is about presenting social interaction with others. There are times when participants feel desperate for having HIV, but this is overcome by developing the successful living. The peers, family members and neighbours are important elements to the practice and maintenance of social interaction:

*No change that happened in my relationship with peers or neighbours, but they used to ask me if I was not having tuberculosis the time I was not taking medications for HIV because I had a chronic cough.*

*When I felt better due to medications, they no longer worried about me, and we now live in harmony. (Participant 2, a 19-year-old girl, rural, horizontally infected)*

Another participant from semi-urban area stated:

*I have a normal relationship with my family members. They never treat me differently; they always advise me, and my mother tries her best to buy fruits for me frequently. My siblings do not get that favour like me but my mother buys and cares for me as much as she can. They care so much, and they never isolate me at all. (Participant 4, an 18-year-old boy, semi-urban, vertically infected at birth)*

## Discussion

This qualitative study explored the lived experiences of AWH in Rwanda using an interpretive phenomenological approach. The three themes that emerged from the study were respectively the burden of HIV, owning my story and successful living with HIV.

### Burden of HIV

This study revealed that participants experienced different reactions immediately after being aware of the positive diagnosis and some fall into shock while others present denial of the diagnosis. It takes time for AWH to become resilient with HIV condition and they present less participation in some activities like those related to social involvement. [25] This is due to the burden of HIV they face, and stigma which make them less abiding to recommended medical protocols like adherence to antiretroviral therapy. The results are consistent with the study conducted by Qiu and colleagues [26] on emotional problems and related factors in patients with HIV and AIDS indicated that it is common for people to present anxious behaviours after learning that they have HIV. The AWH face existential crisis impacting their psychosocial health. They present poverty, poor mental and physical health, stigma, and difficulties with ART adherence.[27]

The participants mainly presented existential crisis, stigma and kept HIV status a secret which were a form of burdens of having HIV. This is supported by a systematic review study of Robinson and colleagues [28] examining the relationship between HIV-related Stigma and the wellbeing of AWH, that revealed strong ties between HIV infection, stigma and disclosure. The AWH reported facing hate and isolation when their HIV status becomes known. However, the study of Ngeno et al. showed the positive impact of HIV disclosure on adherence to antiretroviral therapy and lowering of mortality rate among AWH.[29] Voluntary disclosure of HIV status is an important element of the lived experience of AWH. However, there are many challenges and facilitators of HIV disclosure among adolescents.[30] The disclosure process is frequently difficult and ongoing, comprising challenges such as stigma, rejection anxiety, and confidentiality concerns.[30] Peer support has been shown to be critical in supporting adolescents with the disclosure process.[30]

### Owning my story

Another experience of participants relies on owning their story. The AWH pass through different stages that lead to awareness of HIV infection. In the present study, it was found that early adolescence (age between 10 to 14 years) seems to be the exact period when HIV diagnosis is reported. However, HIV diagnosis may be reported before this age or after, leaving adolescents with multiple dilemmas. In this regard, the study of Hayfron-Benjamin and colleagues,[31] conducted in Ghana showed that the HIV diagnosis and disclosure among caregivers is low mainly because they lack knowledge and guidance regarding the appropriate methods and timing for disclosing HIV status to children and adolescents. In the study conducted by DeSilva and colleagues,[32] in China, it showed the same challenges of HIV disclosure among AWH and their caregivers. The caregivers planned to disclose to AWH at the end of early adolescence (at 14 years)



which is far from recommended WHO guidelines where HIV disclosure to AWH and their caregivers should be done at 6 to 12 years of age.[33–35] After knowing the HIV diagnosis, the participants must make decisions on their health as the only way of staying strong and have good health or spoil it if the decision made is worse. The participants from this study prefer taking medications as prescribed to keep them healthy and free from opportunistic infections. They recommend support groups to guide them in making good decisions for their health. This is supported by the study conducted by Audi and colleagues [36] in Tanzania that showed support groups to have helped AWH in adhering to medications and increase their knowledge and confidence.

### **Successful living**

The successful living is another experience that is faced by the AWH. The AWH experience successful living along their living continuum, with different features of successful living, self-acceptance, behavioural impact, and social interaction. Many of participants have got a vertical transmission of HIV, just from their mothers during pregnancy, during and after birth. They are not happy for getting HIV from their parents [24,37] but this study found that participants who successful live with HIV live a good life with good plans. Participants present diverse characteristics of successful living, but they share self-acceptance in common. This is a complete acceptance of their situation which was labelled by participants as an advanced understanding of the problem (HIV) they have and ability to accommodate it for better morality and energy to plan accordingly. This is supported by the study conducted by Albright and colleagues [38] that found self-acceptance as the end stage of trajectory that starts from self-condemnation and people develop hope followed by self-acceptance. Self-acceptance is a continual process for which participants developed over time and it has been a foundational basis for their behaviour and social interactions with others.

According to the participants, positive behavioural impact was about living peacefully with others and having discipline. Participants' experiences rely on their daily manner of acting towards or with others, that were mainly characterized by non-disclosure and resulted into engaging in unprotected sex during romantic relationship. This phenomenon occurred in participants as denial for having HIV and unwillingness to disclose their HIV status to their loved ones. Adolescents with HIV tend to deny that they have HIV especially after HIV diagnosis. This is supported by different studies that have shown people with HIV at different stages of the condition to deny HIV infection in different ways.[39–41] People with HIV, especially at early stage of their condition, tend not to disclose their HIV status and try to hide all evidence that may prove them to have HIV. Studies have shown this practice of hiding the HIV diagnosis to be common in different settings.[42] In this study, participants' relationship with peers, family members and community remained the same after knowing their HIV diagnosis.

One of the strengths of this study rely on its methodology. An interpretative phenomenology was used to deeply explore the lived experiences of AWH and how they make sense with the social world. In this study, participants' lived experiences were explored, and an analysis was conducted to make this phenomenon meaningful. The limitation of this study is the lack of generalizability of the study results because this study was conducted on a narrow age range using non-probability purposive and snowball sampling.

### **Conclusion**

In this study, findings showed that AWH experience difficult moments when they get HIV diagnosis. As the HIV/AIDS is a chronic and life-threatening condition that people are overwhelmed to develop, those with HIV develop a crisis prior to living a successful life. They experience the burden of HIV and get existential crisis and stigma, leading them to keep HIV status a secret.

The AWH are the ones that master their lived experiences with HIV, and they make decisions to keep a healthy life. Although they pass through difficult moments from denial to self-acceptance, AWH that successfully live with HIV, live in harmony with others and are optimistic for the future.

The care for AWH should focus on their uniqueness and provide preventive and care support based on individual needs. The tailored health education should be provided to AWH during support groups for them to change possible risk behaviours and develop a successful life. The support groups for AWH would be strengthened by establishing tailored care services based on individual needs. More research is needed to explore different characteristics of AWH for which individualised care should consider. This would improve the quality of care leading to the successful living of AWH.

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### Author Contributions

All authors have made substantial contributions to the conception, design, acquisition, and analysis of this study, and interpretation of the data. All authors contributed to the drafting or revising of the manuscript and approved the final version of the submitted manuscript. All authors agree to be accountable for all aspects of the study.

### Conflicts of Interest

The authors report no relevant financial or non-financial interest to disclose.

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