


# The Unheard Stories: Experiences of Young People Living with Human Immunodeficiency Virus in Dealing with Discrimination in the Philippines

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**Purpose:** The aim of this study is to gain an in-depth understanding of the experiences of young people living with the human immunodeficiency virus (YPLHIV) in dealing with discrimination and contribute to a more efficient response.

**Patients and Methods:** We utilised qualitative descriptive research-narrative inquiry. Twenty YPLHIV aged 19 to 24 under treatment from HIV hubs in Metro Manila, Philippines were purposely selected for an in-depth individual interview. Data were transcribed verbatim and manually coded and analysed using narrative thematic analysis.

**Results:** We found that HIV knowledge and beliefs of YPLHIV plays a huge role in their experience. Second, dealing with HIV stereotypes contributed to how they assume judgments from others (perceived stigma) and may have internalised the stigma which alters their belief toward self and the disease. Third, thoughts of suicide, experiencing emotional dissonance, and having difficulty embracing one's identity indicate declined mental health. Fourth, they continuously seek and may have received support from significant others and the community. Some may have directly received or perceived discrimination, but the YPLHIV reported that support received from others plays positively vital role in their journey. Finally, the disease helped change their behaviour and, in turn, brought them to lifestyle change as they are eager to be undetectable and untransmissible (U=U) and perpetually reflect on the ordeal challenge of adhering to treatment.

**Conclusion:** Our study concluded that the stigma and discrimination that YPLHIVs endured were caused by misinformation about the disease and stems from both within themselves and from others around them. Support received from friends, family members, and the community helped them deal with their circumstances. We recommend that efforts be made by both the government and non-government to develop programs distinctly for YPLHIV. Future research may explore the mental health aspect as this has been found concerning in the narratives among young population patients.

**Keywords:** young people, HIV, stigma, discrimination, Philippines

## Introduction

Young People Living with Human Immunodeficiency Virus (YPLHIV) is a term used by Joint United Nations Programme on HIV/AIDS (UNAIDS) and the United Nations Educational, Scientific and Cultural Organization (UNESCO) to define young people with HIV aged 15 to 24 years old. Even though YPLHIV has some needs in common with the younger children and older adults, conceptually and in terms of programs, they represent a group whose needs are complicated, variable, and all too frequently unmet. It is also critical to remember that the phrase “YPLHIV” refers to a sizeable and diverse population that ranges in terms of their ages, genders, developmental stages, levels of maturity, ways in which they caught HIV, and socioeconomic status.<sup>1</sup>

Since 2015, the World Health Organization (WHO) has warned the Philippines that the country has the most rapidly escalating HIV epidemic in the world. The National Youth Commission expressed its concern back in 2016 over the increasing number of young Filipinos testing positive for HIV. According to the data from the Department of Health's Epidemiology Bureau of the Philippines, there were 1454 people who had been confirmed to have HIV in January 2023; 95% of them (1383) were men and 5% (71) were women.<sup>2</sup> Furthermore, 30% (444) of the cases were between the ages of 15 and 24 at the time of diagnosis. Additionally, of the total confirmed cases in the same month, 1431 were acquired through sexual contact of which 998 were males who reported having sex with another male.<sup>2</sup>

Discrimination in relation to HIV has a considerable impact on people living with HIV (PLHIV), as well as those at risk of the infection. Stigma and discrimination were recognised as the primary barriers preventing the development of effective responses since the HIV epidemic.<sup>3</sup> Since the beginning of the spread of diseases, stigma and discrimination among PLHIV have been defined as “the third phase of the epidemic”, and they are just as essential to the response to the global health crisis as the disease itself.<sup>4</sup> The effectiveness of preventative and care services, as well as volunteer HIV counselling and testing (VCT), have all been found to be hindered by HIV-related stigma. Research studies have demonstrated that access to antiretroviral (ARVs) therapies decreases HIV-related stigma. Still, due to limited access to ARV, the barriers are formed, and there has also been evidence reported that stigma is associated with one's hiding of HIV status and steering clear of health care in fear of being identified and stigmatised.<sup>5</sup>

Young people who had encountered stigma were less willing to communicate about their experiences and less likely to seek professional help. Given this, the stigma associated with HIV presents a significant barrier to both the treatment of HIV/AIDS and its prevention.<sup>6</sup> Our study aims to gain an in-depth understanding of YPLHIV and their experiences with discrimination. We used narrative inquiry to understand their experiences through storytelling and gain a deeper understanding of their situation. The research findings may also serve as a guide for private and public organisations in the implementation programs that may raise awareness about HIV, specifically stigma and discrimination, among the public.

## Method

The authors conducted a qualitative descriptive research study utilising narrative inquiry to gather experiences and stories of young homosexual males aged 19–24 diagnosed with HIV and enrolled for treatment in Metro Manila HIV hubs. The entire duration lasted nine months, covering the clinic visits, recruitment, and data gathering (i.e., interviews).

## Research Design

The authors used descriptive narrative research design, a qualitative method that utilises narrative inquiry to help gain knowledge and understanding of human lives.<sup>7</sup> The narrative method incorporates inquiry that generates data in narrative form or inquiry-oriented towards narratives of human experience.<sup>8</sup> This method is suitable for gaining an in-depth understanding of the narrative experiences of YPLHIV on discrimination. The process of telling stories about HIV may evoke powerful feelings and emotions. Finally, narrative research gives participants a voice to articulate sensitive issues and allows authors to understand the world through the lens of others.

## Sample

The authors utilised purposive sampling in the selection of participants based on the set eligibility criteria while achieving variations in their characteristics and experiences to obtain a comprehensive and in-depth investigation of the phenomenon of interest. Participants of the study should be young males aged 19 to 24 diagnosed with HIV and enrolled in HIV clinics within Metro Manila. Through homogenous sampling, the authors were able to examine a particular subgroup in an in-depth way.<sup>9</sup>

Most of the recent cases in the Philippines were males and are located in the National Capital Region (NCR).<sup>10</sup> With the help of the HIV clinic case managers and coordinators, the clients were linked to the researchers after they responded voluntarily to the invitation posted with a brief research background and attached written informed consent, discussing thoroughly their involvement in the study. They are then screened based on the selection criteria set for the study. Inability to meet the inclusion criteria for selection and to give the informed consent form are excluded. A range of 10 to 24 interviews related to HIV stigma can identify substantial codes.<sup>11</sup> Following the iterative process, the initial analysis is

conducted concurrently with the recruitment and data collection to assess theoretical saturation,<sup>12</sup> wherein no new data or data are repeated and no theoretical insight is being collected<sup>13,14</sup> from the experiences shared by YPLHIV in dealing with discrimination. Therefore, the authors concluded the interviews with twenty participants.

## Instrument

Personal information sheets (PIS) and narrative interviewing through storytelling were used to gather data in the study. The PIS collected the participants' demographic profiles containing their date of birth, sex, gender expression, occupation, and residency. Also, PIS helped obtain written reports from the participants about their HIV diagnosis and treatment information and other relevant events. The narrative interviewing process included storytelling from the participants, followed by an interview through questioning—this was meant to elicit new and additional data needed.<sup>15</sup> The semi-structured and open-ended questions enabled an in-depth understanding of the experiences of YPLHIV. The authors sought validation for the PIS and scripts from three experts to ensure error-free in data collection.

## Procedure

After securing ethical approval from the University Ethics Review Committee of Adamson University (2023-02-PSY-16), the authors sent request forms to HIV hubs in Metro Manila. To follow the clinic's protocol and observe professional and confidential ways of handling the clients as guided by RA 11166, or the Philippine HIV and AIDS Policy Act, a licensed psychologist and an expert in HIV research facilitated the individual interview. The call for participants, written informed consent, and overview of the study were sent to the prospective participants through the clinic managers and coordinators to secure voluntary involvement. These are then systematically discussed before the interview, ensuring the participants understand the research protocol. The written informed consent asked for the permission of participants to allow the researchers to use an audio device to document the interview, their involvement, rights, benefits and risks, confidentiality and anonymity measures, data sharing, and other ethical concerns that may arise. By signing the consent form, participants also authorise the researchers to use the records, any observations, and findings found throughout the study for education, publication, and presentation. Hence, all information from responses was agreed upon to remain anonymised for publication and all other presentation purposes. The authors confirm compliance with the Declaration of Helsinki in involving human participants in the study and securing the utmost protection thereof.

The entire duration of the study lasted for nine months, from August 2022 to May 2023. From January 2023 to March 2023, authors visited HIV hubs in Metro Manila for familiarity. The interview with 20 participants was scheduled within three months thereafter the first visit. Each interview took around 20 to 60 minutes. In observance of data privacy and anonymity among the YPLHIV, each participant was assigned a pseudonym. The narrative individual interview was conducted as follows: (a) in the initiation phase, the interviewer asked for permission to record the interview on an audio-recording device, rebrief the participant about the consent form, explained the context of the investigation, and discussed the procedure of the interview, (b) this was then followed by the main narration phase where the participant proceeds to uninterrupted storytelling, (c) next was the questioning phase, allowing the interviewer to ask follow-up questions—this was meant to elicit new and additional material if needed, and lastly (d) the concluding talk wherein the audio-recording was stopped, participant was debriefed, and additional discussions or small talk was developed.<sup>15</sup>

## Data Analysis

Narrative thematic analysis<sup>8,16</sup> was applied by the authors in this study and followed its five coding steps upon transcription of interview recordings. First, the authors began by transcribing the audio recordings and noted the basic patterns and themes. Each participant was given a pseudonym. Second, the authors read the interview transcripts. The authors noted significant details and early impressions of the participants' experiences. Next, the authors manually coded and arranged the data. Based on the codes, the authors discussed initial findings. After completing each transcript, the authors compared and modified their codes. Later, the authors examined the codes for themes. Finally, after analysing the process, the authors organised and improved transient themes. The authors also ensured a logical separation between the various themes and authors identified sub-themes and their relation to the central theme. To strengthen trustworthiness,

experts validated the coding and theming process. Results were presented and the authors sought verification of the analysis from the participants.

## Results

The narratives of YPLHIV highlight the five key themes, (1) role of HIV knowledge and beliefs, (2) dealing with HIV stereotypes, (3) decline in mental health, (4) seeking and receiving support from others, and (5) changes throughout their behaviour. These are described and presented chronologically creating patterns from the stories of the participants.

### Role of HIV Knowledge and Beliefs

YPLHIV shared their experiences about how misinformation, among others, could prolong stigma and discrimination against HIV. According to them, raising awareness and adequately educating people about the disease is one way to eradicate this concern.

#### Hearing Misconceptions (from Others) About HIV

The participants discussed the common misconceptions about how other people understand HIV. The following are the common misconceptions heard from others about HIV transmission,

When you share saliva or utensils with other people, and even just the basic human touch like holding hands, putting an arm over another's shoulder, hugging. (Student, 22 years old, MSM)

If I hold you [...] you will have it too, you' will get infected. There are many people who are not aware that HIV can be transmitted through sex because of semen, which is correct. Most of them think if I touch them, my saliva, using my toothbrush [...] (Student, 19 years old, MSM)

With modern treatment, HIV can be considered a chronic illness that can be managed, but as shared by the participants, they revealed that others believed HIV is a death sentence.

Biggest misconception is that HIV diagnosis itself is the reason why people are dying, not knowing that the complications (when not treated) are. (Accountant, 21 years old, MSM)

#### Campaign to Raise Awareness

With concerns about HIV misconceptions, participants shared the importance of campaigning for HIV awareness. The campaign may include topics on curbing the increasing number of HIV cases, improving the lives of those who are living with it, accessing medical care and treatment, and combating the stigma and discrimination that is often linked to HIV. They expressed hope that misconceptions will be addressed to lessen stigma in the community.

HIV is not treated overnight [...] there is no miracle. Educate them (people in the community) but I think what is more important is to let them know what we are going through [...] because I think through that, they will be more empathetic and understanding about our life and challenges. (Student, 22 years old, MSM)

Maybe [...] counselling or seminars could help [...] to open the minds of the public [...] to break the stigma towards sexually transmitted disease. (Freelance, 23 years old, MSM)

### Dealing with HIV Stereotypes

Awareness, knowledge, and belief (true or not) could be a facet of stigma. This theme includes participants' awareness or understanding of how people in the social world create stereotypes that may result in discrimination. However, YPLHIV tends to internalise these and claim they could be true to their identity.

## Perceived Stigma

The participants shared their subjective awareness of the HIV stigma. This includes their interpretation and understanding, regardless of whether they experience direct or indirect discrimination from other people's attitudes and beliefs about the disease.

[...] because society imposed that having HIV is wrong [...] that it is not expected to have HIV even if it already has medication [...] It is disappointing because people, especially Filipinos, are not that open about HIV. When I tell others that I am feeling that kind of discrimination, it does not bother them. I am part of it. It pains me. And, the information they knew about are not sufficient enough and hurtful. (Student, 21 years old, MSM)

Their knowledge and experience about acceptance as an individual from the LGBTQIA+ has also affected their perception.

About discrimination, even before acquiring the disease, when you say that you are a part of the LGBT, especially when you are gay, there is already a stigma that says "maybe you need to". They are being careful and concerned, and at the same time they will say "Oh, gays can easily get sick because they always want to have sex" or something like that. (Customer service representative, 23 years old, MSM)

Not yet (experience discrimination) because nobody knows yet, but I feel discriminated against especially when I hear about HIV [...], when I hear someone is infected because he is gay and when they say, "you can be the next in line." In that way, I feel like I am being discriminated. (Accountant, 21 years old, MSM)

## Internalised Stigma

The participants internalised the negative stereotypes about HIV. They claim this could be true of their identity and that they have formed negative judgments toward themselves.

I have had a stigma on myself because I do not care about what other people say [...] that stigma comes from inside me. From my fear of myself, it comes from me [...] I said, what is this? I am judging myself, I do not accept myself [...] I remember that was the first time I felt like I did not really love myself. that was my most unlovable phase. (Government Employee, 23 years old, MSM)

I discriminated against myself as soon as I found out. I thought to myself, "You are so stupid", "You are so dumb", "Why did this happen?" "You should be enjoying yourself right now", "Why did you do this to yourself?" [...] I want to tell my parents. I want to tell them. But something inside me tells me not to do it. They might distance themselves from me and get disgusted with me just because I have this [...] that was on my mind: they might distance themselves from me no matter how true they are to me. [...] Maybe they (friends) will tell others, that maybe that is where the discrimination will start in my environment. So it was very very difficult, especially since I am envious. I feel envy whenever I see normal people (Student, 19 years old, MSM)

## Decline in Mental Health

Most HIV programs offered by the organisations focus on medical treatment, as HIV has been long enough regarded as a physical concern, and some do not extend to consider psychological aspects. From the narratives, the experiences of YPLHIV were linked to their poor acceptance of their HIV status, which adds to their difficulties in adjusting to their situation. The stigma (internal and perceived), as described in the preceding theme, seems to have contributed to the decline in their mental health.

## Thoughts of Suicide

The feelings of hopelessness led YPLHIV to have an ideation of committing suicide to address suffering. Many participants have experienced having thoughts of suicide at least once in their lives.

The thought is suicidal because, of course, when you have less you feel like you do not have a purpose in this world and, of course, the judgment of your family. (Accountant, 21 years old, MSM)

[...] to be completely honest -trigger warning, I was [...] I really wanted to die at that time. I think of ways of how I will die painlessly like maybe I will let myself get hit by a vehicle or should I overdose on pills or should I do this and that. But then

your human instinct for survival will take over, I tried running away from it because I will die anyway. What if I kill myself instead? Then realisation kicks in, I suddenly think that I am already enrolled in a university and what my parents would feel if I did it. (Student, 23 years old, MSM)

### Experiencing Emotional Dissonance

The dissonance between what they think is acceptable as per the norm or law and how they truly feel. Participants expressed having uncomfortable emotions.

Emotionally. If there is something I want to do, I want to go out, I want to go to my friends, every time I think I have an illness, that I have a disease. [...] The impact is huge to me because I would not do it anymore [...] not physically, but it was really onto emotional where I have problems; that is why when it comes to responsibilities at home. (Student, 19 years old, MSM)

It had a significant effect on the daily responsibilities. Like before, you were this type of person; you were joyful. You are still the same, but it is different already because of your condition, and you should not let it take over you. (Customer service representative, 23 years old, MSM)

### Difficulty in Embracing One's Identity

This includes cognitive and emotional factors in poorly accepting their HIV status and their current identity. It must be challenging for YPLHIV to embrace their status. Although they identified as different occupations, narratives seem to show similarities.

I felt like crying. I was crying in the other room before because it was like I could not accept it like maybe I did too much. I could not help myself, then I cried over and over again. Then it was like I could not accept that I had it; I even asked the staff here if it was accurate. After a few months, I still have not accepted that I am positive yet, but as time passes, I have accepted it because I am not alone. (Cruise crew, 22 years old, MSM)

It is like I experienced this, so what can I do if it is here already. I cannot just remove it because it cannot be removed easily. (Office staff, 25 years old, MSM)

I am trying but there are cases where I still cannot accept that I am positive. The impact is different when you get reminded that "I used to be normal, now I am HIV-positive. (Student, 21 years old, MSM)

### Seeking and Receiving Support from Others

YPLHIV shared their experiences with the social support they have received or lacked from their loved ones or significant others, other individuals, and the community.

#### Support from Loved Ones or Significant Others

The participants have received different reactions from their loved ones or significant others regarding their diagnosis. Some participants shared the support they have received from their families or significant others. However, some participants also experienced discrimination and financial struggles. As shared by a 22-year-old student, he experienced discrimination and was blamed by his family when he revealed his diagnosis,

I experienced discrimination when the pandemic started. I was stuck at home with my family [...] and I told them about my status. What happened was, they blamed me for it and they told me it was my fault, that I was slutty and because I am gay. They said that it was my fault because I am sexually thirsty. After knowing my status, they began to separate my things from their things, even the utensils that I use for eating. I was not allowed to use the bathroom because they are afraid that they will be infected as well. It was so hard because it came from my family, but I had to adjust. (Student, 22 years old, MSM)

Financial problems can occur mainly for those who do not have a stable source of income. In addition, the expenses these participants have to face for their laboratories, fares, and such,

I don't have [...] a job or stable money, so it is really hard for me to go here. So I had to call my friends to borrow some money. (Student, 19 years old, MSM)

Few participants received unconditional support from their families.

But I am thankful because even though I experienced this, I tested positive, and I was not abandoned. He told me not to think that he would find me repulsive, even though I was sick, he said it was his only request that I take care of myself and take medication. Just like how he helped me, I should also help myself in the same way. [...] Yes, there is. His family knows, but my family does not. I really do not want to open up about it. Fortunately, I have a partner who accepts me and his family as well. They were there for me even before I started working; his mom used to support me. (Working Student, 23 years old, MSM)

Simple acts like that, she (sister) was there to empathise with me and puts herself in my shoes. I felt alone; I felt like I was dying, but she saved me from drowning and from the possible suicide attempt. Then until now, she checks up on me regularly and she was the one that makes excuses to our parents whenever I have to go to the clinic. So all this time, my parents think that I go on dates with my sibling when in fact I am at the clinic. (Student, 23 years old, MSM)

### Support from Others and the Community

The participants described how kind, accommodating, encouraging, and inclusive their communities were. However, some participants expressed their perspectives and experiences about receiving betrayal and lack of support.

He also had sex with someone and the diagnosis [...] was said [...] my information, my name, everything [...] even my story was shared. All of my exes did that to me without my knowledge. My friends and even some healthcare professionals said to seek legal help because it is no longer normal for such events to tell my story, and my information because there is still discrimination. Although it is okay with me, I do not want it to come from someone else. (Student, 21 years old, MSM)

Some participants expressed their gratitude for receiving support from the clinic staff.

I still have a chance; there is medication. Then my social worker told me, "There is a support system and if you cannot face other people, I am here for you. You can text or call me if you need someone to talk to. I am here. I am your older sister and childhood friend, I will help you". And that was when I realised that it was not hopeless. (Student, 23 years old, MSM)

He added,

Starting at 8:30, they will start sending me messages with our code names like: "Patient [code name] please remember to drink your medicine". Another example is that they will call you fifteen minutes before the designated time to take the medicine which is 9:00 p.m. They will keep on ringing you until you confirm that you already took your medicine.

Most participants emphasised that having a support system is essential in their journey.

I think it is very important to have a support system, especially in this day and age when you have no one to cling to but yourself [...] so with that, it will make you comfortable with the feelings that you are having. You do not need to keep it in a jar or hide your feelings deep within yourself. So you can express and feel better (Customer service, 24 years old, MSM)

You need to have people supporting you, to check if you are okay and maybe I am lucky to have those people because there are people who do not have those. So find an effort to build a community, to have a community, to have your support system. (Freelance filmmaker, 24 years old, MSM)

### Changes Throughout their Behaviour

Because taking medication is a lifelong process and adherence to it could be challenging. Diagnosed with HIV may have various behavioural outcomes. Adolescents struggle because they start taking on responsibilities at this age. Through this study, we have discovered some behavioural outcomes.

## Changes in Lifestyle

The participants shared how they altered their lives from having a normal routine to a safe and healthy lifestyle. The participant mentioned that he decided to have an improved lifestyle and made sure that he took his medicine to achieve the undetectable and untransmissible (U=U) of HIV. When a patient reaches this undetectable viral load, it means that the patient will not be able to transmit their disease to anyone,

My lifestyle became a healthy and clean living one. Also, you should not miss drinking your medicine so that you can reach the “undetectable”, as they call it. (Peer navigator, 22 years old, MSM)

Some participants became more cautious about food intake and their engagement.

I have become more careful, so to say, conservative about what I eat as well as more careful about everything I do. (Construction site supervisor, 23 years old, MSM)

I take my medicine after eating breakfast every morning. I make sure that I eat before drinking my medicine because I believe that it helps. I was not eating breakfast way back before going to work. After doing this, it made me more disciplined [...] I could say that sometimes I do not feel like drinking my medicine but despite that, I make sure to drink it (Teacher, 24 years old, MSM)

While others shared helpful activities to keep their sanity and eventually cut vices.

I am left alone with my thoughts. I do journal or write in my diary, reading a book or watching movies or anime in order for me to somehow lighten its impact towards me but when the episodes start, it makes me quiet and then I tried to sleep as much as possible to get away with it. I will run away from it for a while but as soon as I wake up, I will begin to compartmentalise it or the other term that millennials say “we can intellectualise our feelings” which means we can categorise them. (Student, 23 years old, MSM)

So after that, I cut off all my vices like I am a heavy drinker and smoker. I cut it all off drastically. So I pursued a healthy lifestyle, I enrolled myself in a gym. I have been conscious in my life. (Freelance filmmaker, 24 years old, MSM)

## Challenges in Adhering to Treatment

The participants expressed willingness to adhere to their treatment. However, some have worries and have faced challenges. As young individuals who are still attending to their education or their early careers, there are circumstances wherein taking their medication has posed a challenge in their lives.

I think the biggest [...] challenge is scheduling. The schedule here is during Mondays or Thursdays only. So as a student, sometimes the schedule clashes. So [...] sometimes, I need to [...] I need to skip classes so I can go here. (Student, 20 years old, MSM)

Medicine intake because, even though I never missed taking it, there were times that I could not follow the schedule for drinking medicine. (Peer navigator, 22 years old, MSM)

The participants have shared similar side effects of the medicine. This was identified as an addition to their challenge in adhering to their treatment.

In the first three years, I was on LTE, and that was when there were effects such as dizziness, stomach cramps, warm feeling. Every night I experienced vomiting, even at school, because there were already classes at that time. I had a fever for almost one month due to the dizziness caused by the side effect of LTE. I cannot tolerate it. I cried every night because every time I experienced the side effect, it reminded me that I have it—that I have HIV. Then, after that, I pushed for the LTD to come out because before I switched to LTD, I was also diagnosed with depression. (Student, 22 years old, MSM)

## Discussion

Living with HIV as a young person can be particularly daunting, as they may lack the necessary knowledge and awareness about the disease. This knowledge gap may contribute to misconceptions and misinformation, increasing



stigma and discrimination. People with low levels of education were more likely to have misconceptions about HIV transmission.<sup>17</sup> In our study, all participants reported that others tend to believe contracting the disease is a death sentence. Misconceptions and beliefs surrounding the disease lead to stigma and discrimination. As a result of their HIV status, they concealed it from their loved ones and the community because of their fear of stigma and discrimination. The participants explained that raising awareness is a way to deal with the people who treated them differently because of the disease. It is a way to combat the stigma they are receiving. Additionally, sharing their existing knowledge is essential to combat stigma and discrimination.<sup>18</sup>

The emotional and mental well-being of the YPLHIV was negatively impacted by the stigma and discrimination they face daily. Many participants absorbed the discrimination adversely and have acquired a poor opinion of themselves (internal stigma). Stigma has caused most YPLHIV to feel guilty and ashamed, becoming hesitant to express their views and fearful that they will not be taken seriously. As a result, some cases of HIV status are not being disclosed.<sup>19–21</sup> Other participants have stated that they experienced feeling emotionally challenged and having suicidal thoughts. These experiences were also identified as poor acceptance of one's HIV status, low social integration, suicidal ideation, and feelings of grief, fear, stress, mistrust, and worry about the future.<sup>22</sup> It was indicated that it can be difficult for anybody, including PLHIV, to avoid some of the harmful ideas and beliefs that exist around HIV. A significant number of participants mentioned that they had the idea of committing suicide as a way to escape their situation. Similar to the recent study in China, that suicidal ideation is common among PLHIV, confirming that the syndemic effect of psychosocial health is a known predictor.<sup>23,24</sup> PLHIV tend to isolate themselves from “normal” people to limit adverse reactions or stigmatisation.<sup>25,26</sup> The majority of the participants' initial reaction after receiving their diagnosis was that they found it challenging to accept their HIV status.

Regarding social support, the vast majority of YPLHIV have stated that most of their loved ones or significant others were concerned and surprised but later received their support, which helped them feel more valued despite the diagnosis. It was emphasised that the support received by YPLHIV from their loved ones or significant others is vital in assisting them in developing a sense of worth and coping with social problems.<sup>27</sup>

Numerous participants shared that their situation was bearable because of the encouragement and inclusiveness within their community. The social environment is one of the most essential forms of support for the YPLHIV.<sup>28</sup> Some participants have stated their experiences regarding the lack of support from their loved ones or significant others, friends, the community, betrayal, and financial problems. It is important to emphasise that most participants acknowledged receiving support from the community aside from their family and significant others. In line with this, adolescents living with HIV who receive social support from family, friends, and the community are likely to develop a higher sense of self-worth.<sup>29,30</sup>

YPLHIV had their share of how their condition changed their lives. Those who regularly consume healthy foods in proper proportions can better tolerate HIV medicines, maintain a healthy weight, and feel better overall.<sup>31</sup> Eating nutritious food can ease medication side effects, help maintain a healthy weight, and boost the immune system.<sup>32</sup> One of the participants mentioned that he takes additional vitamins to help his immune system fight the virus. Moreover, it was noted that having a healthy lifestyle and adhering to continuous medication will lead to a high possibility of reaching that undetectable stage of their condition.

Antiretroviral (ARV) therapy, an HIV medication, involves taking medicines every day to suppress the virus. Although treatment helped maintain the immune system, adhering to it came with challenges and worries. One participant shared that testing has been costly since his work asks for his CD4 results. In contrast, another participant who is currently a student shared that transportation to visit the treatment hub was a challenge due to a lack of financial resources. No matter how long a participant had lived with HIV, lack of financial resources, being too busy, and medication (ARV) side effects were common problem.<sup>22,33</sup> Poverty made it challenging to survive in the day-to-day, which complicated the participants' choice to adhere to their treatment.<sup>34</sup> The participants reported experiencing side effects of their respective medications. Side effects are one of the obstacles to adolescents receiving effective therapy.<sup>35</sup> This includes nausea, dizziness, vomiting, and stomach cramps. These caused the YPLHIV to experience difficulty falling asleep and have negatively affected their academic performance.

## Conclusion

The result of the study implies that the discrimination that the participants have faced stems from both within themselves and from others around them. The knowledge and support they received from loved ones and from the community has a huge role in helping them in their journey to dealing with discrimination. Future researchers may explore further the mental health aspect, focused on thoughts of suicide, emotional dissonance, and identity building among YPLHIV. These factors may contribute to adherence to treatment and accountability in improving one's well-being. Government and non-government agencies may help campaign awareness of the disease at the community level, strengthen treatments, nutrition, and mental health counselling programs, and create support groups distinctly for YPLHIV.

## Strengths and Limitations

This study has opened a platform to hear the voices and stories of YPLHIV. It was stated in Goffman's theory of social stigma (2019) that having HIV is like having a mental illness, which is a deeply discrediting attribute. In line with that, this study proved that knowing the diagnosis of YPLHIV has contributed to the decline in their mental health.<sup>36</sup> This study is vital as it will help other people be aware of what the real story behind YPLHIV and discrimination is. However, the inclusion criteria for participants eligible for the study do not accurately represent the whole YPLHIV community. The findings narrated in this study may not be generalisable and are not representative of all male YPLHIV.

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## Disclosure

The authors declare no conflicts of interest in this work.

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