

# The Lived Experience of Youths with HIV/AIDS and the Challenges in the Context of Jimma Town; A Qualitative Phenomenological Study

## Abstract

This paper is aimed at reporting on the challenges, perception and lived experience of youths living with HIV/AIDS in Jimma town. Since individual perceive and experiences are interrelated and interconnected factors and co-occurring with daily life. To identify the problem using phenomenological in-depth interview technique on lived experiences among youths living with HIV/AIDS on different aspects of life beginning from the first time test result to the current psychological, emotional, behavioral, social support, medication adherence and substance use. The study population were youths with HIV/AIDS and using antiretroviral therapy medication in a selected health care institution. Some youths may avoid social contacts and do not seek their much-needed social support since they believe that they are not worth of respect and care from anyone. As a result, youths living with HIV/AIDS may live in despair and a constant fear of rejection, and yet lack social support that they need. The trend of substance abuse is very common in youths living with HIV/AIDS because of the psychosocial wellbeing, biological, emotional, spiritual, cultural, social, mental and material aspects of experience.

**Keywords:** HIV/AIDS • Youths • Psycho-social • Antiretroviral therapy

## Introduction

There were 38 million people living with Human Immune Virus (HIV) in 2019 globally, up from 30.7 million in 2010, the result of continuing new infections. Of the people living with HIV 36.2 million were adults and 1.8 million were children under age 15 [1]. In Ethiopia more than one million are estimated to live with HIV. Though some were getting Anti-Retroviral Therapy (ART) medication but mental health care and psycho-social support for People Living with HIV (PLHIV) is neglected due to numerous reason like COVID-19 pandemic, conflicts, displacement, and political instability throughout the country [2]. HIV infection itself affects physical, psychological, social, and spiritual elements of an individual's life, as well as those of their caregivers, and health care systems in low-resource settings often have difficulty helping clients to avoid or sufficiently address these challenges. The past pandemic COVID-19 had significant impacts on public health and general population; leading to neglected care for those individuals who have

HIV/AIDS. HIV infection can result in a chain of psychosocial issues in PLHIV, such as stigma, leading to non-disclosure, and poor adherence to treatment, which leads to reduced viral suppression and disease progression finally causing premature death [3].

Bad life experience is common among PLHIV and very difficult in the context of youths. However, relationship problems such as self-stigma, loneliness, avoidant personality, and substance related problems, adjustment problems, stress, and HIV-associated psychological disturbances have a profound effect on adherence to ART treatment outcomes. While having this need for early identification and intensive intervention for social emotional concerns in people with HIV/AIDS, there exists a shortage of personnel trained to provide psycho-social services with early initiation of testing for HIV. With HIV progression, PLHIV and their caregivers have an increasing need for physical, emotional, and spiritual support, which can overwhelm the resources available to them. A coordinated approach between formal and informal support

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systems is needed to support PLHIV and their caregivers through the death and dying process and the grief and loss afterwards [4-6]. Health care providers, either at the primary care level can play a pivotal role in assessing the perception and experience of PLHIV and linking people to the needed services by using the standard protocol [7].

Specifically, this study sought to explore the perception and lived experience of youths living with HIV/AIDS in preparing pre-ART counseling to provide proper adherence for people living with HIV/AIDS, and evaluate the perceptions of clients regarding the stigma, and instruments necessary for preparing psychologists to provide social, psychological, emotional assessment and mental health services in early clinical settings.

## Materials and Methods

This study utilized a phenomenological qualitative approach that is a method for illuminating the specific experiences and identifying phenomena through how they are perceived by the actors in a situation. In order to produce trustworthy and insightful findings in this study, various consecutive phases were followed specifically; familiarization with data, generating initial codes, searching for themes, reviewing the theme, defining and naming themes, and producing the final reports. In this study, a total of twelve sample respondents were participated purposively who had more experience and real or perceived exposure for HIV/AIDS who disclosed themselves. Thus, the criteria for selection of the participants were Youths on ART and volunteer to expose them. The study was undertaken in

the Jimma university medical center which is the largest hospital in the South West Ethiopia and working in collaboration with local and international stakeholders. The interview protocol checklist consists open ended questions (e.g., how do you describe your experience during the first-time disclosure? To what extent do you worry about being infected by HIV? You may have a clue about the mechanism of infection? How do you perceive HIV/AIDS and how your perception influences your life or work? Do you have sexual partner and if so, you disclose your status? What mechanism you use not to infect others?). The researchers developed data collection instruments through reviewing various related literatures and WHO HIV/AIDS comprehensive care benchmarks.

The qualitative data were recorded, translated, transcribed and analyzed using reflective thematic qualitative analysis technique by using the Atlas version 7. With ethical considerations of explained purpose of the study to all participants' and consents were obtained at first step. All participants were assured that the information obtained would remain confidential and no personal information would be disclosed.

Participants were also told that there was no need to provide any personal information to the interviewer, including name, surname, phone number and address.

## Results and Discussion

The study participants are youths who are attending ART clinic in Jimma university medical center. Majority of the participants were male and from secondary school (Table1).

Table 1. Biographic data of the participants.

Participants	Gender	Age	Educational background
P1	M	16	Grade 9
P2	M	17	Grade 11
P3	F	17	Grade 10
P4	M	14	Grade 8
P5	F	14	Grade 7
P6	F	17	Grade 9
P7	M	16	Grade 8
P8	M	15	Grade 9
P9	M	15	Grade 8
P10	F	17	Grade 11
P11	M	17	Grade 10
P12	M	15	Grade 8

Totally 12 HIV positive youths participated in this study. As a result of data analysis, 2 main themes and 8 sub-themes were identified, which include: Life experience (first disclosure, emotional change, fear of consequence, suicidal ideation), and the perception (influence on daily life, coping style, healthy life style, stigma).

### Theme one: Experience

**During first exposure:** The results of this study showed that patients experienced unpleasant experiences in the face of receiving a positive diagnosis of the HIV. Patients' unpleasant experiences at that moment include emotional shock, fear of the consequences, feeling guilty, discouragement and escape from reality [8]. Some youths reported that they didn't have any emotional reaction when disclosed test result positive.

In this study, some of the participant's idea was explained in verbatim. P2 male client from the grade 11 reported that "I was taking my ART drug for the past 17 years but was told that I am HIV positive at the age seven. At that time I didn't realize anything good and bad about HIV/AIDS. For this reason I didn't face any emotional challenge during exposure".

Another participant P10 female participant from grade 11 had different reaction during her first disclosure. She reported that "I was informed that I am HIV positive when my classmate is talking to some other classroom students. Since beginning that day I stopped taking medication whom I was taking every night realizing that the drug is for HIV. I asked my mom the reason why I am taking the medication and she took me clinic and the doctor told me that I am HIV positive and should take my medication every day.

**Emotional change:** With these different levels of emotional reaction, people living with HIV can sometimes experience heightened levels of emotional and psychological issues including fear, guilt, abandonment, lack of worth and harassment. People with HIV have a higher chance of developing mood, anxiety, and cognitive disorders. Depression is one of the most common mental health conditions faced by people with HIV. It is important to remember that mental disorders are treatable. Receiving an HIV diagnosis can be life changing and somebody may feel many emotions, sadness, hopelessness, or anger. HIV may challenge the sense of well-being or complicate existing mental

health conditions. HIV, and some opportunistic infections, can also affect your nervous system and can lead to changes in your behavior [9].

P10 reported that "At that time I was depressed and even thought to end my life but latter I blamed my mom and dad for the positive result and even dropped school with fear of rejections from friends".

**Fear of consequence:** Nosophobia is the extreme and irrational fear of developing an ailment that either is or is perceived as life threatening [10]. Common culprits include cancer, kidney disease, and HIV. Fear of illness, stigma, and being discriminated against or judged negatively if a test shows that they have HIV are some of the obstacles. HIV phobia can lead folks to avoid spaces, places, and activities that they have deemed "higher risk" (even if those activities aren't higher risk). So, another symptom is an aversion to certain things. It can also lead to excessive consumption of news, information, and media about HIV and AIDs. The lack of information and awareness combined with outdated beliefs lead people to fear getting HIV. Additionally, many people think of HIV as a disease that only certain groups get. This leads to negative value judgements about people who are living with HIV. Over time, this low level of inflammation takes a toll on the body, putting the person with HIV at greater risk for health conditions such as cardiovascular disease, kidney disease, diabetes, bone disease, liver disease, cognitive disorders, and some types of cancer. Stigma is a damaging social phenomenon [11]. In the case of People Living with HIV (PLWH), stigma has negative effects on health outcomes, including non-optimal medication adherence, lower visit adherence, higher depression, and overall lower quality of life.

P1 "the first fear comes to my mind is suffer with the symptom of HIV/AIDS, before that I prefer peaceful death before symptom appears"

**Suicidal ideation:** When one is tested positive for HIV, one can think that the whole world has ended and that there is no hope for the future, whilst others see it as stepping stone to a better life [12]. It is true that with the correct care and support, living with HIV can be made easier. However without this, the results can be catastrophic. HIV/AIDS continues to be associated with an under-recognized risk for suicidal behavior. Suicidal behavior among people living with HIV/AIDS is not only a predictor of future attempted suicide and completed suicide,

but it is also associated with poor quality of life and poor adherence with antiretroviral therapy [13]. The thought of ending life is very common in this study. Majority of the participant especially in the first exposure experienced suicidal thought around first disclosure of their status while some others experience after stigma and discrimination [14].

P6 “I thought that the whole world has ended and that there is no hope for the future”

### Theme two: Perception

And the perceptions HIV/AIDS-infected individuals has numerous impacts on daily life, coping style, life style and stigma at different level.

**Influence on daily life:** People living with HIV/AIDS frequently experience stigma and discrimination, especially in the surrounding community [15]. With these different levels of stigma to deal with, people living with HIV can sometimes experience heightened levels of emotional and psychological issues including fear, guilt, abandonment, lack of worth and harassment. This triggers psychological problems, including anxiety, depression, and the risk of suicide. The stress associated with living with a serious illness or condition, such as HIV, can affect a person's mental health. People with HIV have a higher chance of developing mood, anxiety, and cognitive disorders. Depression is among the most common mental health conditions faced by people with HIV [16].

P3 female respondent “the life to me is very difficult now, all students from school segregated me. I am so lonely, nobody understands me, and nobody talks me. For this reason I prefer staying home than going to school. When I stayed home I feel free”.

P4 “it seems to me everybody is talking about my issue for this reason I am not comfortable in every scenario to participate in different activities freely”.

In this research we explored that some of the respondents stigmatize themselves simply with the fear of rejection and abandon.

**Coping style:** Despite the availability of antiretroviral drugs, globally HIV/AIDS has become among the top causes of morbidity and mortality while they struggle to overcome significant challenges that affect their ability to live independently [17]. HIV affects not only

physical and psychological aspects of health but households, communities, and the development and economic growth of nations. Some others in these study reported that their coping strategy is having faith with GOD. While some others participate in sport and other leisure activities with their friends [18].

P9 “may be GOD created me for the reason, I don't worry much for what was happened in my life because I didn't bring it. Now I am serving in church and still my life is good.”

**Life style:** In this study some participants reported that they hide themselves under using different types of substance. Substance use disorder treatment, medical care, housing, mental health care, nutritional care, dental care, ancillary services, and support systems are very important for clients with HIV [19]. Staffs need training on the availability of these services in their communities to effectively provide appropriate referrals and services, case managers. It may need additional training to work in an integrated setting or across HIV and SUD specific settings. Stable rehabilitation for an individual with HIV and a SUD could be the determining factor in maintaining treatment adherence [4]. It also includes trainings on techniques to build rapport and therapeutic alliance, such as motivational interviewing, reflective listening, and using understandable language. The above mentioned are very hard to get in developing country like Ethiopia because of the limited resource [20]. But it could be easy if given attention to create awareness on symptoms and illness of substance related problems beside with the interactions of medication he/she is using for ART and how to cope with stigma coming from the community, institution and even from some professionals and self.

P3 “living with HIV/AIDS is somewhat difficult, thanks to physician now I am healthy even feels nothing about HIV. Around the time I was told that I had HIV/AIDS everything was dark to me. Through process I realized that living with HIV/AIDS is nothing and reshaped my life with positive life styles as I recommended from my physician. Then life gets easier, my confidence increased, started generating income in small shop and started supporting my grand mom whom was my care giver since my mother was died when I was child and I didn't know my dad in person”.

**Stigma:** Stigmatizing attitudes are still pervasive

within the world especially in Africa and mostly in Ethiopia and can negatively impact an individual's willingness to seek care and remain engaged in it. Stigmatizing beliefs may be related to fear of transmission or ideas about who is at risk for being diagnosed with HIV. Supporting medication adherence is important for people living with HIV to take their HIV medication every day, exactly as prescribed. This is what counselor can do to support them in establishing a medication routine and sticking to it. Also needs what might have and how individual can help them stay healthy. These phenomenological studies shows status of mental wellbeing, stigma and discrimination among PLWHA Jimma town, Ethiopia. Health professionals' mental health skills, attitude, stigma and discrimination on individual, family, or group counseling; stress management and coping sessions; educational sessions; home visits; and respite care. Peer support groups in particular have been used successfully as part of a comprehensive psychosocial support program in different studies. Therefore, addressing the psycho-social issues for People Living with HIV (PLHIV) is central to a comprehensive approach to their care and support. Talking openly about HIV can help normalize the subject. It also provides opportunities to correct misconceptions and help others learn more about HIV. But be mindful of how you talk about HIV and people living with HIV. We can all help end HIV stigma through our words and actions in our everyday lives. Lead others with your supportive behaviors.

P1 "ohh..... Stigma is very bad. It makes life miserable, I was stigmatized and discriminated as much as possible the whole my childhood life. Even told from neighbors not play with their children because they knew that I am HIV positive. At that time I didn't know anything about, simply they warn me not get in their house. Because this always I cry and I wish my mom is alive".

## Conclusion

Youths Living with HIV/AIDS (YLWHA) are more likely to experience emotional, behavioral, and cognitive difficulties due to both the direct neuropsychiatric effect of the HIV/AIDS infection on their brain functioning and the indirect effects related to a wide range of stressors, including the complexities of adolescence. The purpose of this study is to examine the perception and lived experiences of youths living with HIV/AIDS in Jimma town through

exploring social, psychological, emotional status in youths with HIV. The results of this study showed that patients will experience unpleasant phenomenon in the face of the positive diagnosis of the disease and will be subjected to severe psychological pressures that require attention and support of medical and laboratory centers. This could include shock, numbness, denial, anger, sadness and frustration. It's perfectly normal and understandable to feel any of these. Some people might also feel relief that they finally know the truth. You may also feel isolated and alone, even if you have family and friends around you. Patients will experience severe psychological stress in the face of a positive diagnosis of HIV. Patients who are diagnosed with HIV are prone to make a blunder and dreadful decisions. AIDS patients need emotional and informational support when they receive a positive diagnosis. As a piece of bad news, presenting the positive diagnosis of HIV required the psychic preparation of the patient. Many people living with HIV can expect to live as long as their peers who do not have HIV. Studies show that a person living with HIV has a similar life expectancy to an HIV negative person providing they are diagnosed in good time, have good access to medical care, and are able to adhere to their HIV treatment. People with HIV may experience challenges with achieving and maintaining viral suppression. Some of these challenges include missing HIV medical appointments, needing but not receiving other important health care services, or missing doses of HIV treatment.

Therefore, the researchers tried to recommend the concerning bodies in Ethiopia especially to Jimma university medical center ART clinic to link those youths with supporting agents in psycho-social, financial and empowering the victimized youths through developing self-esteem creating internal strength in surprising viral load, decreasing public and self-stigma, bringing behavioral change, avoiding emotional challenges and creating substance free life.

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## Authors' Contribution

WA designed the study, collected data, analyzed the data and reviewed the manuscript. GA designed the study, supervised data collection, analyzed the data, drafted the manuscript and critically reviewed the manuscript. FA designed the study, supervised data collection, analyzed the data, drafted the manuscript and critically reviewed the manuscript.

## Funding

The research was conducted by financial support of Jimma University. The funding body has no role in the design of the study and collection, analysis, and interpretation of data and in writing the manuscript.

## Availability of Data and Materials

The datasets used and analyzed during the current study is available from the corresponding author on reasonable request.

## Ethics Approval and Consent to Participate

The research protocol was approved by Institute of Research Board (IRB) of Jimma University. After obtaining permission from the hospital; the selected participants were called by with the help of psychologist to quite place prepared for interview. Participants were given adequate information about the objective of the study and encouraged for genuine responses. Since the study has no reporting experiments on humans or the use of human tissue samples, therefore the only informed verbal consent was sought from all participants before running the interview and even for reporting for different bodies and publications. Participants had given the right to decline to participate or to stop responding to the interview if they felt discomfort. Luckily; none of them were found to decline taking part in the study.

## Consent for Publication

Consent for publication was taken from all concerning bodies.

## Competing Interests

The authors declare that they have no competing interests.

## References

1. Govender RD, Hashim MJ, Khan MA *et al.* Global epidemiology of HIV/AIDS: A resurgence in North America and Europe. *J Epidemiol Glob Health.* 11, 296-301 (2021).
2. Mirkuzie AH, Ali S, Abate E *et al.* Progress towards the 2020 fast track HIV/AIDS reduction targets across ages in Ethiopia as compared to neighboring countries using global burden of diseases 2017 data. *BMC Pub Health.* 21, 1-10 (2021).
3. Mutumba M, Musiime V, Lepkowski JM *et al.* Examining the relationship between psychological distress and adherence to anti-retroviral therapy among Ugandan adolescents living with HIV. *AIDS Care.* 28, 807-815 (2016).
4. Baingana F, Thomas R, Comblain C. HIV/AIDS and mental health. (2005).
5. Organization WH. The World Health report: Mental health: New understanding, new hope. (2001).
6. Pagano L, Caira M, Offidani M *et al.* Adherence to international guidelines for the treatment of invasive aspergillosis in acute myeloid leukaemia: Feasibility and utility (SEIFEM-2008B study). *J Antimicrob Chemother.* 65, 2013-2018 (2010).
7. Olley BO, Zeier MD, Seedat S *et al.* Post-traumatic stress disorder among recently diagnosed patients with HIV/AIDS in South Africa. *AIDS Care.* 17, 550-557 (2005).
8. Imani B, Zandi S, Khazaei S *et al.* The lived experience of HIV-infected patients in the face of a positive diagnosis of the disease: A phenomenological study. *AIDS Res Ther.* 18, 1-8 (2021).
9. Giulino PU. Individual clinical issues. In HIV and Social work. *Routledge.* 165-181 (2014).
10. Sirri L, Grandi S. Illness behavior. *Adv Psychosom Med.* 32, 160-181 (2012).
11. Ullah AA, Huque AS. Stigma, discrimination and HIV or AIDS: An empirical investigation of Asian immigrants and refugees in Canada. *Int J Human Rights*

- Healthc.* 17, 286-299 (2024).
12. Humphreys K, Blodgett JC, Roberts LW. The exclusion of people with psychiatric disorders from medical research. *J Psychiatr Res.* 70, 28-32 (2015).
  13. Gizachew KD, Chekol YA, Basha EA *et al.* Suicidal ideation and attempt among people living with HIV/AIDS in selected public hospitals: Central Ethiopia. *Ann Gen Psychiatry.* 20: 1-8 (2021).
  14. Nkporbu AK, Korubo IE, Stanley CN. Pattern and prevalence of psychiatric comorbidity among People Living with HIV (PLWHIV) at the University of Port Harcourt Teaching Hospital (UPTH). *World J Adv Res Rev.* 17, 697-708 (2023).
  15. Fatoki B. Understanding the causes and effects of stigma and discrimination in the lives of HIV people living with HIV/AIDS: Qualitative study. *J AIDS Clin Res.* 7, 2 (2016).
  16. Egbe CO, Dakum PS, Ekong E *et al.* Depression, suicidality, and alcohol use disorder among people living with HIV/AIDS in Nigeria. *BMC Public Health.* 17, 1-3 (2017).
  17. Amuche NJ, Emmanuel EI, Innocent NE. HIV/AIDS in sub-Saharan Africa: Current status, challenges and prospects. (2017).
  18. Bekker LG, Alleyne G, Baral S *et al.* Advancing global health and strengthening the HIV response in the era of the sustainable development goals: The International AIDS Society-Lancet Commission. *The Lancet.* 392, 312-358 (2018).
  19. Aidala AA, Wilson MG, Shubert V *et al.* Housing status, medical care, and health outcomes among people living with HIV/AIDS: A systematic review. *Am J Public Health.* 106, e1-e23 (2016).
  20. Belayneh Z, Mekuriaw B, Mehare T *et al.* Magnitude and predictors of common mental disorder among people with HIV/AIDS in Ethiopia: A systematic review and meta-analysis. *BMC Public Health.* 20, 1-1 (2020).