

9-30-2021

## Uptake of health services by youth living with HIV: A focused ethnography

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[10.1111/inr.12638](https://doi.org/10.1111/inr.12638)

This is an Accepted Manuscript of an article published by Taylor & Francis in *International Nursing Review* on 30 September, 2021, available online: <https://doi.org/10.1111/inr.12638>

Zgambo, M., Arabiat, D., & Ireson, D. (2021). Uptake of health services by youth living with HIV: A focused ethnography. *International Nursing Review*, 68(3), 299-307. <https://doi.org/10.1111/inr.12638>

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This is the peer reviewed version of the following article: Zgambo, M., Arabiat, D., & Ireson, D. (2021). Uptake of health services by youth living with HIV: A focused ethnography. *International Nursing Review*, 68(3), 299-307., which has been published in final form at <https://doi.org/10.1111/inr.12638>. This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Use of Self-Archived Versions. This article may not be enhanced, enriched or otherwise transformed into a derivative work, without express permission from Wiley or by statutory rights under applicable legislation. Copyright notices must not be removed, obscured or modified. The article must be linked to Wiley's version of record on Wiley Online Library and any embedding, framing or otherwise making available the article or pages thereof by third parties from platforms, services and websites other than Wiley Online Library must be prohibited.

## **Uptake of health services by youth living with HIV: a focused ethnography**

### **Abstract**

**Background:** Although several programs have been initiated to increase the uptake of health-services among youth living with human immunodeficiency virus in the world, disparities in access to these care services still exist.

**Aim:** This study aimed to explore the experiences of young people as they attend the human immunodeficiency virus clinic and to identify factors affecting their uptake of health services in southern Malawi.

**Methods:** A focused ethnography was conducted to collect data from 20 youths living with human immunodeficiency virus and aged between 15–24 years through one-on-one in-depth interviews and casual observations. The interviews data were analysed thematically following transcriptions.

**Findings:** Two themes emerged to describe the factors that facilitated or hindered the uptake of HIV-health services. The first theme: Facilitators to the accessibility and utilization of HIV services consisted subthemes of *Health personnel-related factors* and *Innovative healthcare delivery approach*. The second theme: Barriers to utilization and accessibility of HIV service comprised of the following subthemes: *Ignorance of health services available*, *Clinic-related factors* and *Consumer-related factors*.

**Conclusion:** Efforts to support health services that are youth-friendly and easily accessible are needed to increase uptake, decrease mortality, prevent disability, and promote the wellbeing of youth living with human immunodeficiency virus.

**Implications for nursing practice and policy:** Approaches used with this population should be youth-centred and multifaceted, recognizing both the psychosocial challenges and the vulnerability that many youths in Malawi experience.

**Keywords:** Barriers; facilitators, HIV-health services, youth, living with HIV, HIV risk behaviours, HIV transmission, focused ethnography, Malawi

## **Introduction**

The youth population globally continues to be disproportionately affected by the human immune-deficiency virus (HIV) epidemic and associated deaths (World Health Organization [WHO], 2020). In 2017, the majority of the 590,000 youth, who acquired HIV globally, were in sub-Saharan Africa (SSA), with 30% of the total new infections occurring among youth aged from 15-24 years (WHO, 2019a, the Joint United Nations Programme on HIV and AIDS [UNAIDS], 2018). Similarly, Malawi, a landlocked country in south eastern Africa, had 14,000 new HIV cases among youth aged 15-24 years in 2018, which accounted for one-third of all new HIV infections in the country (UNAIDS, 2018). To reduce the disproportionate prevalence of HIV among youth, the WHO recommends several strategies to facilitate the accessibility and usability of health services among this population. These strategies aim to reduce the transmission of HIV through improving access to condom use, increasing anti-retroviral therapy (ART) adherence, and providing health education and social support (WHO, 2019a). Following this, many health care systems in SSA have integrated sexual and reproductive health services with HIV care for youth living with HIV (YLWHIV) to increase service availability and eradicate the infection (Akutukwasa et al., 2019).

Despite the efforts above, SSA countries continue to lack the means of maintaining sufficient utilization and accessibility to these services by their youth population (Akutukwasa et al.,

2019). Stigma, lack of confidentiality, inherent poverty, poor clinical reception, lack of governments' protection against child abuse, and societal misconception about sexual reproductive health services, have all been reported in SSA as barriers to service access and utilization (Nakigozi et al., 2015, Sullivan et al., 2019). The under-utilization of the provided services negatively impacts on HIV knowledge, access to condoms, and ART adherence for controlling HIV transmission (Rodger et al., 2019).

To eradicate HIV by 2020, UNAIDS, in partnership with the WHO established the 90-90-90 targets (UNAIDS, 2014). The global objectives are to diagnose 90% of people living with HIV, treat 90% of people with HIV and suppress the virus in 90% of those on ART. In Malawi, several programs such as 'Voluntary Counselling and Testing', 'Provider-initiated Counselling and Testing', "HIV Diagnostic Testing", in addition to the recently introduced "HIV Self-testing" have facilitated better identification, follow up and treatment of individuals living with HIV (Mandiwa and Namondwe, 2019, UNAIDS, 2016). Malawi, as a country, has an HIV prevalence rate of 9.2% (UNAIDS, 2018). More than half of the total population (17.5 million) are young people below 18 years of age (National Statistical Office, 2018). Youths who are on ART constitute 86%; however, 20% of these have not attained viral suppression and therefore, are at a higher risk of infecting others (Government of Malawi Ministry of Health, 2018, UNAIDS, 2019).

Compared to adult patients, the young population in Malawi is less likely to access services, adhere to treatment, or to maintain a suppressed viral load (UNAIDS, 2019). For those who are already attending HIV programs in Malawi, attrition is the primary challenge faced by HIV programs (Alhaj et al., 2019). Mitigating the attrition rate in youth is significant in the fight against HIV. Using the 90-90-90 targets successful maintenance of a suppressed viral load depends on successfully engaging youth in treatment and ongoing support programs. Looking

into the future, combined limited uptake of the HIV-health services and incidence of HIV infections among youth has the potential to result in a higher HIV burden for Malawi and the southern African region. The gap in YLWHIV's usability of Malawian health services identifies the need for further innovative approaches to HIV programs. We, therefore, undertook a qualitative study to explore the current experiences of YLWHIV attending HIV clinics to identify factors affecting the uptake of HIV-health services.

## **Methods**

### ***Study Design***

This study was part of a larger study whose primary objective was to understand the socio-cultural context of HIV risk and sexual behaviour among YLWHIV in Malawi. The study employed a focused ethnography design and used semi-structured interviews and casual observations to collect data. Focused ethnography evolved from traditional ethnography and is designed to assist researchers in defining people's cultural behaviours through a description of thoughts and views in more depth within their smaller cultural groups (Lofland et al., 2006). Unlike traditional ethnographies, in focused ethnography, a cultural group is a cluster of persons sharing common experiences and characteristics, and individuals within the group may neither know each other nor be connected by geographical and ethnic boundaries (Knoblauch, 2005). The youths attending an HIV clinic was the cultural group from where participants were drawn. Comparatively, in focused ethnography, a lesser amount of time spent observing participants in the field is accepted, and one or more rigorous data collection methods such as in-depth interviews, observations and focus group discussions can be included (Knoblauch, 2005). We further utilized the consolidated criteria for reporting qualitative research checklist (COREQ) (see Supplementary file) to identify and report the relevant methodological aspects of the study (Tong et al., 2007).

## ***Setting***

This study was conducted in an HIV clinic in a district hospital in Mwanza District in southern Malawi. According to the Malawi National Statistical Office (2018), Mwanza district covers an area of 756km<sup>2</sup> and has a population of 130,949 with half of these aged below 18 years. The current HIV prevalence is 7.4% of the total population, predominantly affecting the female gender. In 2018, two-thirds of the population did not have a formal educational qualification, and only 10% of these completed education to the primary school level. As such, most people in Mwanza district depend on subsistence farming, and the district is famous for citrus fruits grown for commercial purposes (Faulkner et al., 2009). The clinic was located at Mwanza District Hospital: a referral hospital for all medical centres in the district. The clinic opened its doors for YLWHIV (10-19-years-old) one regular Saturday every month and everyone from Monday to Friday.

## ***Sample and recruitment***

Three nurses at the HIV-clinic were approached and asked to assist with the recruitment of participants. The nurses were briefed on the study objectives and recruitment criteria/procedures. Inclusion criteria were limited to YLWHIV attending the clinic aged between 15 and 24 years and aware of their HIV-positive status ( $\geq$  six months). Participants were excluded if they were cognitively disabled or had significant speech or hearing problems. In total, 26 potential participants were purposively identified and provided with consent/assent forms and information sheets. Participants  $<$  18 years were given an additional consent form and were required to obtain their parents' consent. Of the 26 potential participants, only 22 returned the signed consent/assent forms. One participant was excluded related to a significant hearing problem, and another was unable to attend the interview session when scheduled.

Based on sample sizes used previously in similar studies, the resultant sample of 20 participants was deemed adequate (Conte et al., 2015, Kallakorpi et al., 2018).

### *Data collection*

Data collection was done from January to May 2019. One-on-one in-depth interviews, audio-recorded, were conducted in vacant private consultation rooms at the clinic. All interviews were conducted in Chichewa dialect by the first author, who was a competent language user and had undergone extensive training in qualitative data collection methods. Interviews lasted between 21 and 56 minutes, casual observations were also recorded using field notes, researcher reflective notes and sketches. Half of the participants had repeat interviews with the researcher to clarify or add information. This second researcher contact helped participants to relax, open up and to develop a better rapport, as no relationship existed before the first interviews. The interview guide consisted of open-ended questions to allow participants to describe their clinic visits and experiences. The participants were asked to recall one visit to the clinic and describe their experiences. It included questions about what was helpful or problematic and to share some examples. At the end of each interview session, the researcher invited participants to talk about anything they considered essential for improving the health system from their experiences.

All study materials, including the interview guide, were developed in English and translated to Chichewa (local language) using the guidelines by Douglas and Craig (2007). The guide was piloted with two participants who were not included in the main participant group, and questions were modified as necessary for improving clarity. Topic probe questions were used as tools for clarification and for extracting explanation and depth of information, these also facilitated further narration, for example, ‘what about condoms?’.



### ***Data analysis***

The first author transcribed the recorded interviews verbatim, and participants checked their transcripts to verify what was communicated before translating into English. Bilingual translators bound in a confidentiality agreement did the forward and back translation of transcripts following the WHO translation guidelines (WHO, 2019b). The authors then explored the data to identify and extract relevant themes and thematic analysis was manually and inductively carried out using the guidelines by Braun and Clarke (2006). Raw data from interviews and field notes were coded and categorized; categories were merged to formulate core categories, which after discussion between authors became themes (see Figure 1) (Braun and Clarke, 2006). All authors analyzed data independently and regular meetings were held to discuss and agree on emerging themes. The authors were all females. The first author was a doctoral student with a Master's Degree, while the second and third authors were researchers with Doctorate Degrees and years of research experience at the university.

### ***Ethical consideration***

Ethical approval to undertake the study was obtained from Edith Cowan University Human Research Ethics Committee in Australia (#20628) and the National Committee on Research in Social Science and Humanities in Malawi (#P.12/18/340). Permission to conduct the study was further obtained from the Mwanza District Health Management Team. Participation relied on the provision of verbal and written informed consent/assent and parental consent where applicable. Recruiting nurses explained the study information to the participant before giving them the research packs. The interviewer re-explained the study information and clarified any concerns before interviewing. Participants were instructed to use fictitious names in identifying themselves. The name of participants' schools and villages were also assigned an alias during data transcription for confidentiality.

## **Findings**

### **General characteristics of the participants**

This study included 20 participants (ten females and ten males aged 15 to 24 years) who met the inclusion criteria. Although the sample size was predetermined, data saturation was reached after the first 15 participants completed their interviews. Only 30% of the participants were married; however, 90% of the total sample size was sexually active. Most participants were unemployed and did not complete primary school education (see Table 1). Seven participants, who identified as employed, were either in small-scale businesses or casual hard labour such as gardening, fetching water and breaking rocks for building purposes. The distance between the clinic to participants homes ranged from five minutes to >2 hours walk.

### **Themes**

Two main themes emerged from the analysis, A) Facilitators to accessibility and utilization of HIV services which comprised of Subthemes: *Health personnel-related factors* and, *Innovative healthcare delivery approach*, and B) Barriers to utilization and accessibility of HIV service which consisted of the following Subthemes: *Ignorance of health services available*, *Clinic-related factors* and *Consumer-related factors* (see Figure 1).

### **Main theme 1- Facilitators to accessibility and utilization of health services**

#### ***Health personnel-related factors***

Eleven participants stated the health workers treated them positively, which they perceived as encouraging. A positive experience at the clinic meant a warm welcome, clear guidance regarding what to do or where to go, helpful assistance to access services and being spoken to respectfully. The positive experience was perceived to bring reassuring feelings and

alleviate worries in some participants and predisposed the youth to think well of staff and comfort in returning to the clinic.

*'On my first visit, the HIV counsellor was really helpful. She opened my medical file, weighed me.... yes, weighed me. She took me to the place where we get medication. She got it for me while I just waited. Then, she brought me back right there'* (Gonjetso).

### ***Innovative healthcare delivery approach***

Delivery of health education included singing songs and dancing by the health educators to engage clients, and this was an entertaining way of educating and motivating the youth. A variety of health education topics were given in this manner, which was narrated as *'What I like here is seeing people dance, sing and I like it when they teach us how to give medications to our children. We also learn new information. Dancing makes me forget problems'* (Mary).

Four of the six school-going participants were excited with the youth clinic run on Saturday because it did not interfere with weekday school attendance. Attending this clinic was preferred over the adult clinic because a free lunch was provided, no adults attended (privacy issues), and there was the possibility of making friendships with peers. Meeting peers with a similar condition was beneficial for their self-confidence and socialization, which brought a sense of belonging and support.

*'I am happy to be found in a group of friends at the clinic who understand me....and these kinds of friends are scarce at home'* (Chimwemwe).

Participants further discussed the benefits of flexibility in accessing health services at the youth clinic, especially by those who needed early appointments because they had

home commitments. This flexibility extended to married couples who were able to collect medication for their absent spouses:

*'My wife collects pills for me. We discuss and decide that one of us should stay at home to look after the child.... They [nurses] said one can collect medication for both of us when we are busy'* (Funsani).

## **Main theme 2- Barriers to HIV-health services utilization**

### ***Ignorance of the available health services***

Participants discussed the availability of HIV related services at the clinic. Although the majority of participants knew most of the available HIV-health services, one-third of respondents were unaware of the availability of ART counselling, Saturday youth HIV clinic, and condom education. ART counselling services were commonly known to the youth who had a history of missed medication, as Maya stated: *'I used to miss pills. They counselled me, and I don't miss taking my medications anymore.'* Similarly, when Dalitso was asked why he did not attend the youth clinic, he said: *'It is because I didn't know.... I've never heard about it'*. Another participant denied ever receiving condom education.

### ***Clinic-related factors***

The perceived negative attitude of health workers provoked feelings of anxiety among participants and created feelings of discomfort and lack of trust in health providers. This included occasions of being shouted at by staff.

*'Some health workers have a bad attitude. We come in the consultation room, they shout at us, yet, they already know that we are young, this is worrisome'* (Chimwemwe).

The clinic operating system was a significant negative factor discussed by the participants. This was a walk-in clinic, and appointments were usually given without specific times. Therefore, the consultation was typically based on a first-come, first-served basis. However, “socially famous people” or “clients” known to and favoured by health workers would not observe this rule but queue jump causing delay to other clients and being described as “*unfair*”. The slow-paced queue to the consultation room, overcrowding of the waiting area and the inadequate number of healthcare workers caused clients to spend extended periods (up to seven waiting hours) at the clinic. The clinic was always overwhelmingly congested, with only one or two nurses assigned to attend each day (fields notes-observations).

*‘You come early in the morning, even without taking breakfast, hoping to be assisted first and return home to do other stuff. Health workers and their relatives just come at any time to get their medications before us. This annoys me, why do people do this? We all deserve same services.... I was the first today, but many people who came after me have collected their medication and left before me’ (Mary).*

Older youth were more worried about spending long periods waiting at the clinic than the younger youths because of multiple commitments such as businesses. Most participants mentioned coming to the clinic hours earlier than the official clinic opening time (07:30-08:00 am) to book their place. It was also noted that no opening hours were advertised at the clinic, and the clinic started anytime between 0800 to 0900 hours (fieldnotes- observations).

*‘I would arrive here around 6 am and wait for the nurses to come.... which is painful.... we spend a lot of time here; we usually leave the clinic at 1 pm. I walk ....I would be arriving home at 3 pm’ (Mada).*

Although the adult HIV clinic was meant for people above 19 years of age, some youth below 19 years of age attended this clinic, either because they were not listed under the youth program, or they were unaware of the program's existence. For instance, three of the female participants aged between 17 and 18 years, who were not schooling attended the adult HIV clinic. Of the three participants, one had been married previously, the other was unmarried, and the last was not married but pregnant. The pregnant participant was previously attending the youth clinic and was transitioned to the adult clinic without knowing why:

*Previously, we attended the clinic with people of different age groups .... Things got better when they started the youth HIV clinic. I am given different appointment dates from youth clinic....maybe because I don't go to school. I just let it go (Lonjezo).*

Participants' lack of comfort in attending the adult HIV clinic was associated with exposure, embarrassment, and stigma. Dissimilarly, encountering clients at the clinic with distorted physical appearances because of HIV or ART, increased participants' fear that they would have similar body disfigurements in the future:

*'I get worried when I see fellow clients with appearances. I fear that I will look like them too....what really happens that someone should look like that while on treatment' (Maya).*

### ***Consumer related factors***

Participants further shared how a lack of money for transport resulted in long walks to the clinic. A total of 14 participants reported walking over 30 minutes to reach the clinic, while nine participants walked between 60 to >120 minutes. Although walking to the clinic was common among this sample, it was time-consuming and not appealing to participants because of the weather and bad roads. During data collection, daytime temperatures above 30

Degrees Celsius, torrential rains and a destructive cyclone were recorded (Field notes-Observations)

*'The means of transportation is difficult, especially when it is raining, and our roads are bad. We still walk because we need help'* (Fusani).

Other hindrances to accessing healthcare services depended on individual youths' characteristics, such as shyness, forgetfulness, not seeing the importance of treatment or labelling self as young with a lack in self-confidence to ask health workers for condoms. Generally, unmarried participants found it difficult to collect condoms from the clinic, rather inconsistently sourced condoms from their friends in the villages:

*'Health workers can leave condoms here [table], but I don't take them. I fear that they may laugh at me or think that I like.... [sex]. I get condoms from friends in the village.... If I have condoms, I share with buddies too. It is a common practice, and you can notify friends if you have them like 'hey, I have condoms with me, want some?'* (Jonasi).

## **Discussion**

The findings of this study highlighted factors of infrastructure, communication and sensitive service provision that may facilitate or impede the uptake of HIV-health services from the youths' perspectives. Condom education and ART counselling, which play significant roles in preventing HIV transmission by reducing condom-less sex and optimizing ART adherence (Rodger et al., 2019), were unknown to some participants. Lack of service awareness may have resulted from ineffective communication between providers and clients; this upholds a previous study which found that healthcare providers do not adequately meet the information needs of a young population (Hodgson et al., 2012). Health providers need to continuously

discuss and inform YLWHIV (and ascertain their understanding) of the available services through pamphlets or face-to-face.

Other identified barriers were embedded within the incumbent health system and professionalism of the organization, including the negative attitude of some health workers, uncontrolled injustice at the waiting area and limiting some services (like condoms and youth HIV clinic) to specific YLWHIV. Such perceived unprofessional attitudes of health workers and negative experiences at the clinic are known to have a corresponding negative effect on health-seeking behaviours in youth (Toska et al., 2015). There is a significant need to reinforce professional standards and discipline for health workers with poor attitudes and equip them with skills and knowledge to provide user-friendly services to the YLWHIV.

Although HIV-health services in Malawi are currently cost-free, socioeconomic barriers to access HIV care were highlighted by most participants, who generally, belonged to low economic class. They were unable to meet the financial demands of transport, which made making a walk to the clinic a necessary. Similar findings related to transport issues were reported in other countries such as Uganda (Nakigozi et al., 2015). In resource-rich countries such as the United States of America (USA) and Australia, specific disadvantaged groups of YLWHIV are often impacted with similar issues, mainly those living in poverty, in society with a limited number of services and without adequate health insurance coverages (Centers for Disease Control and Prevention, 2020, Lea et al., 2019). Currently, YLWHIV are experiencing the effects of two pandemics – HIV and Corona Virus Disease 2019, which has crippled socioeconomic systems at a global, national and individual levels (McKibbin and Fernando, 2020). Thus, expediting strategies aimed at improving HIV-health services by alleviating socioeconomic barriers are warranted to prevent attrition. We suggest the introduction of community mobile HIV clinics that should be run by enthusiastic and



competent youth-friendly providers. Mobile clinics have proved to mitigate cost-related deterrents to the uptake of HIV-health services as evidenced in HIV testing programmes (Ostermann et al., 2011).

In this study, some non-schooling, married (or married before) and pregnant participants, were transitioned to adult HIV clinic irrespective of age or preference. Such youth are transitioned to the adult clinic to prevent 'bad influence' on young peers (Masese et al., 2019). Transitioning youth to an adult clinic in this manner risks disengagement with support services and cessation of treatment programs because YLWHIV fear reproof and exposure to parents/adults when attending the adult HIV clinic (Saber et al., 2018). We argue that all YLWHIV should attend a youth focussed clinic irrespective of disparities in personal characteristics to promote fairness in accessing appropriate health services and increase youth satisfaction with the provided services.

### **Limitations and strength of the study**

This study has limitations; therefore, the results should be read with the ordinary caution of a single report from one HIV-clinic in the southern region of Malawi. Every effort was made to select reasonably representative HIV-health services for the YLWHIV, and to pay special attention to elements that might be more generally relevant across other HIV services in Malawi. Nonetheless, how this clinic was or was not representative of the broader health care services cannot be ascertained from within the study itself. Second, there is a possibility that some YLWHV, who were not in HIV programs, may have different perceptions from views of participants in this study. Third, due to the sensitive nature of HIV and cultural factors, some youth may have provided socially accepted answers. Likewise, the subjectivity during data analysis and interpretation cannot be ruled out due to the nature of the study design.

Nevertheless, this study is one of a kind that used the perspectives of the youth to determine their barriers and enablers of uptake of HIV-health services. Therefore, the study findings would inform the development of nursing or policy interventions for delivering youth-friendly HIV-health services. The participants of this study were all encouraged to be honest with their answers during interviews. The research team members were involved throughout the processes of data analysis and reviewed the codes and themes emerging from the transcripts, which helped to improve the credibility of the study findings.

### **The implication for practice and policy**

The findings of this study have several implications for practice, policy, and research. First, approaches used with this population should be youth-centred and multifaceted, recognizing both the psychosocial challenges and the psychological vulnerability that many youths in Malawi experience. To do so, nurses and health providers should consider distributing condoms to all YLWHIV to maximize access to condoms. This will increase the availability and use of condoms in the youth community and help decrease HIV transmission to sexual partners. Second, frontline nurses need to inform the youth of available health services provided by clinics as they may lack awareness about specific services. Third, the Malawi Ministry of Health needs to consider reinforcing policies that promote professional discipline and provide youth-focused training of health workers at the clinic. This could be through staff establishment of clinical incidents disclosure and an anonymous feedback system between clients, nurses, and the Ministry of Health. The open disclosure and feedback framework is known to improve professional conduct and quality of care in the USA, Australia and United Kingdom (Harrison et al., 2019, Harrison et al., 2017). The community health providers need to work with- and sensitize the community, group leaders and parents to accept and encourage youth to participate in activities that reduce HIV transmission. The Malawi Ministry of Health should introduce policies that eradicate barriers based on lack of transport that restrict

access to the clinic, possibly by the establishment of youth-focused mobile clinics or telehealth services. To reduce perceived barriers, the public health department needs to develop in consultation with youth and youth focussed health care workers new initiatives for enhancing communication skills and patient engagement with health services. Another effective measure is in achieving quality assurance and accreditation of the health services to provide consistent quality of care and assure ongoing patient satisfaction (Shaheen et al., 2020)

Lastly, a qualitative study with HIV clinic service providers is warranted to gain a complete understanding of both facilitators and barriers to the uptake of HIV-health services amongst youth. Future research can explore the preferences and effectiveness of accessing HIV health-services at adult clinics by married, pregnant or non-schooling youth as this will assist in planning for interventions to help this vulnerable group.

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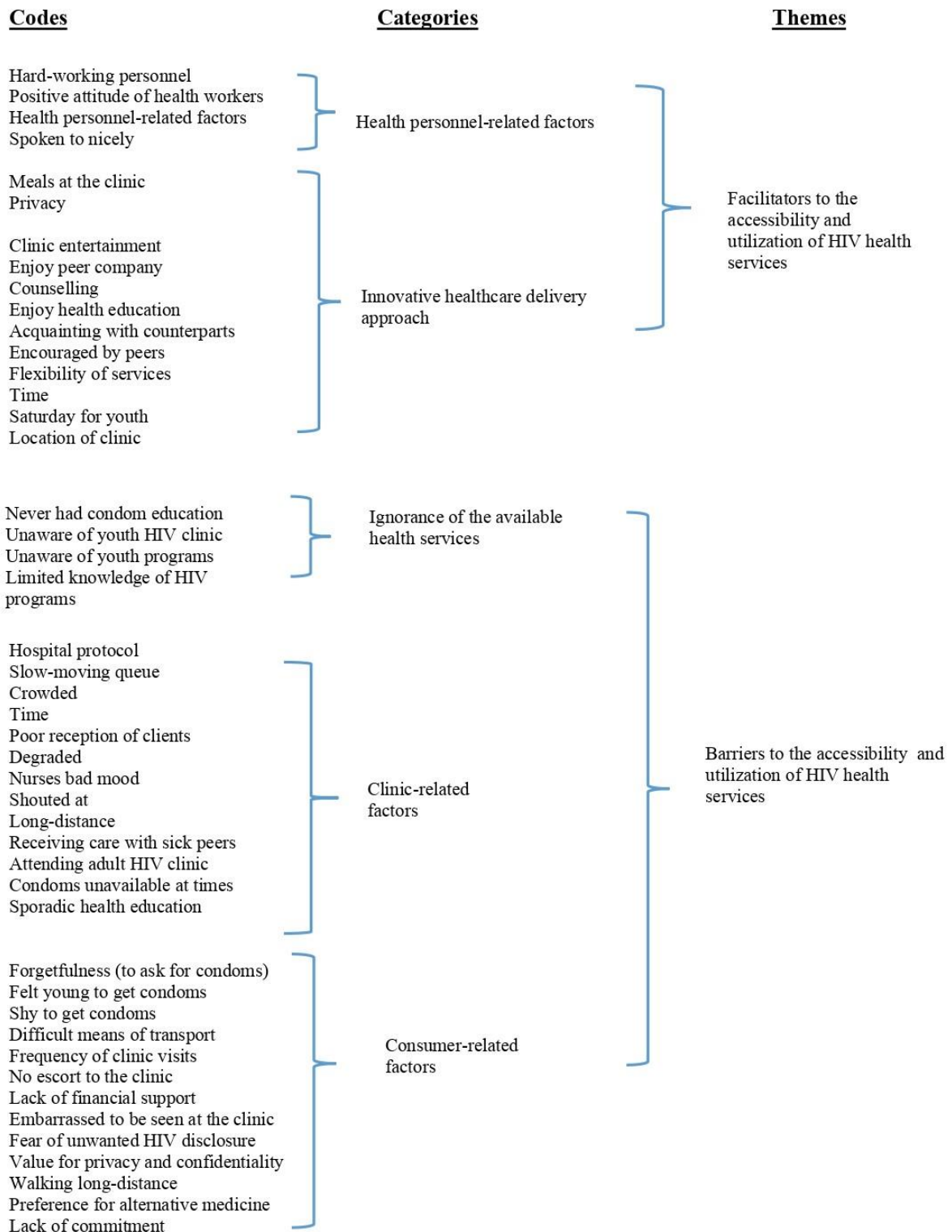
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**Table 1: Sample characteristics**

<b>Characteristics</b>	<b>N (%)</b>
<b>Age (years)</b>	
15-19	10 (50%)
20-24	10 (50%)
<b>Gender</b>	
Male	10 (50%)
Female	10 (50%)
<b>Marital status</b>	
Married	6(30%)
Not married	14 (70%)
<b>Employment status</b>	
Unemployed	13 (65%)
Employed	7 (35%)
<b>Educational level (grade)</b>	
Primary 1-4	4 (20%)
Primary 5-8	10 (50%)
Secondary 1-4	5 (25%)
Tertiary	1 (5%)
<b>Educational status</b>	
Ongoing	6(30%)
Non-schooling	13(65%)
Completed	1 (5%)
<b>Distance from home to the clinic</b>	
5-15-minute walk	4(20%)
>15- 30 minutes' walk	2(10%)
>30- 60 minutes' walk	5(25%)
>60 minutes to >2hours	9 (45%)



**Figure 1: data coding tree**