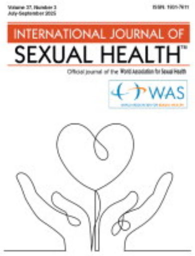

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Challenges and Enablers of Antiretroviral Therapy Adherence Among Ethiopian Adolescents: A Qualitative Study

Cheru Tesema Leshargie[a,b,c], Daniel Demant[c,d], Sahai Burrowes[e], Nakachew Mekonnen Alamrew[a] and Jane Frawley[c]

[a]Department of Public Health, College of Health Science, Debre Markos University, Debre Markos, Ethiopia; [b]Rural Health Research Institute, Charles Sturt University, Orange, Australia; [c]School of Public Health, Faculty of Health, University of Technology Sydney, Sydney, Australia; [d]School of Public Health and Social Work, Faculty of Health, Queensland University of Technology, Brisbane, Australia; [e]Public Health Program, College of Education and Health Sciences, Touro University California, Vallejo, CA, USA

ABSTRACT

Background: Despite global decline in acquired immunodeficiency syndrome (AIDS)-related mortality, *adolescent* (10–19 years) *deaths are rising*. Adolescents living with Human Immunodeficiency Virus (ALHIV) face unique antiretroviral therapy (ART) adherence challenges, *especially in low-income settings*. This study explores factors influencing ART adherence among Ethiopian adolescents.

Methods: A qualitative study was conducted with 12 ALHIV from August to September 2021in Ethiopia's Amhara Region. Semi-structured interviews were conducted, transcribed, and analyzed using deductive coding and an interpretive phenomenological approach.

Results: The analysis explored three prominent themes: (1) culture and religion, (2) connection and belonging, and (3) stigma and mental health. These themes collectively provide a comprehensive understanding of the barriers and facilitators influencing adolescent adherence to ART. Cultural and religious beliefs, especially those held by parents, such as misconceptions about long-term medication use, side effects of ART, and illness as divine punishment, acted as barriers to adherence. On the other hand, connection and belonging through family, community support, and shared experiences with peers facilitated adherence. However, stigma—whether internalized, experienced, or anticipated—caused isolation and mental health challenges, creating significant barriers to treatment adherence.

Conclusion: This study sheds light on the multifaceted challenges faced by adolescents in adhering to HIV treatment, including cultural misconceptions, social and familial dynamics, and mental health barriers. Addressing these issues requires culturally sensitive health education and fostering environments that promote connection and support. Community-based interventions and peer networks can play a pivotal role in strengthening adherence, while stigma-reduction efforts are essential to addressing the mental health challenges adolescent's encounter. The findings highlight the need for a holistic approach integrating health education, stigma reduction, provider training, and mental health support to enhance adherence and outcomes for ALHIV.

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Antiretroviral therapy adherence; Adolescents; HIV/AIDS; Ethiopia; stigma and mental health; qualitative study

Introduction

Human immunodeficiency virus (HIV) remains a major global public health challenge despite decades of intervention (Cohen et al., 2008; Pandey & Galvani, 2019; WHO, 2019a). In 2020, 1.5 million people acquired HIV, and 680,000 died from HIV-related causes (WHO, 2024). The sub-Saharan Africa region accounts for more than 70% of HIV infections (Cohen et al., 2008; Mengesha et al., 2023; Pandey & Galvani, 2019; WHO, 2019a), with adolescents experiencing a particularly concerning rise in incidence (Idele et al., 2014). That year alone, an estimated 150,000 adolescents aged 10–19 acquired HIV

CONTACT Cheru Tesema Leshargie chertesema@gmail.com Department of Public Health, College of Health Science, Debre Markos University, Debre Markos, Ethiopia.

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(UNICEF, 2025), and AIDS-related deaths among adolescents aged 15–19 more than doubled since 2000 (Patsy & Rita Ann, 2016). Eastern and Southern Africa account for approximately 60% of adolescent HIV cases globally (UNICEF, 2016). Both vertical transmission (during gestation, delivery, or breastfeeding) and horizontal transmission (through sexual contact or blood exposure) contribute to adolescent HIV infection (ASHM, 2024; Janini et al., 1998).

Due to improved diagnosis and treatment, many perinatally infected children now survive into adolescence, increasing the burden in this age group (UNICEF, 2025).

Antiretroviral therapy (ART) suppresses viral replication, improves immune function, and lowers transmission risk (UNICEF, n.d). However, treatment effectiveness requires adherence rates above 95% (Paterson et al., 2000). Poor adherence can lead to drug resistance, treatment failure, increased HIV transmission, and fewer therapeutic options (Chen et al., 2017; Iacob et al., 2017).

Despite the global target of 95% treatment coverage and viral suppression by 2025 (KFF, 2024), only about 73% of people living with HIV receive ART (WHO, 2024). In Ethiopia, while 74% of the estimated 670,000 people living with HIV were on ART by 2019 (Mantell et al., 2023), adolescents living with HIV (ALHIV) face unique adherence barriers that jeopardize national and global HIV goals (Frehiwot et al., 2014).

Barriers to ART adherence among adolescents and adults include pill burden, stigma, medication side effects, costs, drug resistance, lack of nutritional support, and poor health literacy (Bezabhe et al., 2014; Galea et al., 2018; McKinney et al., 2014; Okawa et al., 2018; Shubber et al., 2016). Strategies such as using community health workers, social support groups, mHealth outreach, and adolescent-specific services have shown promise (Calvetti et al., 2014; Ferrand et al., 2017; Zanoni et al., 2017). However, adolescents often face greater psychosocial and developmental barriers, such as difficulty accepting lifelong treatment or isolating themselves from support systems (Kourrouski & Lima, 2009; Kranzer et al., 2017; Valencia & Cromer, 2000).

Ethiopia, adherence remains a challenge due to healthcare access issues, medication shortages, and stigma (Shimels et al., 2023; Tiruneh & Wilson, 2016). Adolescents living with HIV (ALHIV) are underserved in HIV services, with limited access to testing and counseling, weak linkages to HIV care, inadequate health education, and a lack of adolescent-targeted services (Association of Chartered Certified Accountants, 2013; Children & AIDS, n.d; Frehiwot et al., 2014; Vogt et al., 2017; WHO, 2016, 2019b). They are often deprioritised compared to adults within Ethiopia's HIV care and treatment programs (Frehiwot et al., 2014; WHO, 2019b). Most health providers receive limited training in adolescent sexual and reproductive health (Frehiwot et al., 2014), further compounding the health.

This qualitative study explores factors that facilitate and hinder ART adherence among adolescents in northern and central Ethiopia. It aims to uncover nuanced, context-specific, and patient-centered factors influencing ART adherence in this population, acknowledging the distinct cultural, social, and developmental dynamics of the region. Communal values, religious beliefs, and strong parental authority often shape adolescent decision-making, including in health-related matters (Yeshanew, 2024). For example, belief in holy water as a healing practice, reliance on traditional medicine, and perceptions of chronic illness as divine punishment or fate remain influential (Baheretibeb et al., 2022). Adolescents, even those in urban areas, are often embedded in tightly knit family structures where independent health choices may be discouraged (Presler-Marshall et al., 2020). At the same time, Ethiopia's youth population faces challenges in navigating tensions between traditional expectations and modern health practices, especially regarding stigmatized conditions like HIV (Adraro et al., 2024). Adolescents are developmentally distinct from adults, undergoing rapid physical, emotional, and cognitive changes that impact their risk perception, autonomy, and health behaviors (Backes & Bonnie, 2019). These developmental transitions, combined with stigma and secrecy surrounding HIV, create unique adherence challenges that cannot be fully understood through adult-focused research (Shimbre et al., 2024). While this study centers the lived experiences of adolescents, the analysis draws conceptually from the socio-ecological model to help situate barriers and facilitators of adherence across individual, interpersonal, and systemic levels.

By prioritizing adolescents' voices and experiences, this study seeks to uncover barriers and facilitators potentially overlooked by quantitative approaches. The findings are anticipated to inform evidence-based policymaking, guide the development of culturally sensitive interventions, and contribute to a holistic understanding of the complexities surrounding ART adherence in the region.

Methods and materials

Study design

A qualitative phenomenological research design was utilized in this study.

Participants and recruitment

We recruited 12 adolescents aged between 15 and 19 years who were aware of their HIV status and received care from selected HIV clinics in the Amhara Region. The region has five comprehensive specialized hospitals (CSHs) offering an extensive range of services to a population of more than 20 million, namely the University of Gondar CSHs, Felege Hiwot CSHs, Dessie CSHs, Debre Birehan CSHs, and Debre Markos CSHs.

Only adolescents living with HIV who had been under follow-up care for a minimum of six months were eligible for inclusion in the study. The participants were recruited through healthcare providers. We purposively selected male and female adolescents living with HIV for our interviews. To ensure participants' well-being and uphold ethical research standards, we excluded adolescents with severe mental health conditions that had been clinically diagnosed. This decision was based on ethical guidance to minimize potential harm, as some participants might have found discussions of sensitive topics distressing in the absence of appropriate mental health support (Farmer & Kashdan, 2015). At the time of data collection, referral and follow-up support services were limited in the study settings, which posed additional risk. We acknowledge that this exclusion may limit the representativeness of our findings and inadvertently omit the voices of a vulnerable subpopulation. Future research should seek to include adolescents with mental health conditions through the use of appropriate safeguards, including trained mental health personnel and standardized tools to assess mental health status (Harvey & Gumport, 2015).

Sample size determination and sampling technique

A purposive, criterion-based sampling strategy was employed to recruit adolescents who could provide rich, relevant insights into the phenomenon of ART adherence (Saunders et al., 2018; Vasileiou et al., 2018). In total, more than 687 adolescents aged 15–19 years were receiving ART follow-up at the selected facilities. During the two-month data collection period, 287 adolescents had scheduled clinic appointments and were eligible for recruitment. Of the 63 adolescents approached during their follow-up appointments at health facilities, 18 expressed willingness to participate, and in-depth interviews were conducted with 12 of them.

The final sample size was guided by the concept of information power, which suggests that the more relevant and richer the information participants hold for the research aim, the fewer participants are needed (Malterud et al., 2016). An iterative approach was used for data collection and preliminary analysis, and recruitment proceeded until thematic saturation was achieved, defined as the point at which no novel themes or insights emerged, and interview data became redundant (Given, 2015; Saunders et al., 2018).

Data collection instruments

To guide data collection, we developed a semi-structured interview guide (see Supplementary File 1) based on the socio-ecological framework (Bandura, 1986; Brown et al., 2013; Castro et al., 2015; Centers for Disease Control and Prevention, 2015), which informed the exploration of factors influencing ART adherence at individual, interpersonal, community, and structural levels. The guide was also informed by a review of existing literature on adolescent ART adherence in Sub-Saharan Africa, and relevant questions were adapted from previously validated instruments where applicable to enhance contextual relevance and depth. The guide included open-ended questions covering broad thematic areas such as HIV knowledge, psychosocial challenges, and adherence-related barriers and facilitators. Probing and follow-up questions were used to delve deeper into participants' experiences and perspectives. The interview guides and consent materials were initially prepared in English and then translated into Amharic by a qualified translator. To ensure linguistic accuracy and conceptual fidelity, a second translator cross-verified the translation through a back-translation process.

Data collection

The interviews were conducted in August and September of 2021. An experienced interviewer conducted the interviews in the local language (Amharic). The interviews were held in a quiet and convenient hospital setting after a health facility visit. Audio recording was employed for transcription purposes, while contemporaneous field notes were taken to inform subsequent analyses. Each participant was systematically assigned a unique identification (Ahmed et al., 2021) number by the interviewer. The average interview duration spanned 38 minutes, with individual sessions ranging from 33 to 41 minutes.

Data quality assurance

To ensure the quality and trustworthiness of the findings, Sim and Sharp's strategies were applied (Tracy, 2010). Before analyzing the data, the translated documents were reviewed. The quality of the coding and theme formation was also ensured by the principal investigator and a PhD student researcher (CTL and GDK). Three authors (CTL, JF, and DD) discussed and confirmed the findings. The interviews were transcribed by two authors, CTL and NMA, who checked their work against each other to make sure the transcription was correct and to fix mistakes or differences.

Data analysis and reflexivity

All audio recordings were transcribed verbatim by CTL and NMA and annotated with nonverbal cues such as laughter, crying, and pauses. Phonetic transcriptions of dialects and filler words were retained to preserve contextual meaning. The transcripts were translated into English and imported into NVivo software for coding and analysis. We employed thematic analysis following the six-phase approach described by Braun and Clarke, using an inductive, semantic coding strategy to allow patterns and categories to emerge directly from the data. The socio-ecological framework was used to guide the interpretation of findings, helping to structure themes across individual, interpersonal, institutional, and societal levels (Baral et al., 2013; Braun & Clarke, 2006).

This framework was selected due to its relevance in understanding the multi-level influences on ART adherence among adolescents and the interactions between personal behavior and social context (Baral et al., 2013). Prior to formal coding, the lead researcher (CTL) engaged in repeated readings of the transcripts to gain familiarity with the data and began developing preliminary codes based on the frequency, prominence, and richness of discussions. A code–recode process was employed to improve reliability. Two additional researchers independently reviewed the codes, and any discrepancies were resolved through team discussion until consensus was reached.

We also acknowledged and addressed researcher reflexivity throughout the analysis. All researchers brought prior experience in adolescent health and HIV care in Ethiopia. Regular reflexive meetings were held to discuss how our professional backgrounds and assumptions might influence data interpretation, and strategies were implemented to minimize potential bias and enhance analytical rigor.

Although direct member checking with participants was not conducted due to ethical and logistical constraints, engagement with local health providers and community representatives during the analysis phase served as a form of informal validation, helping ensure that emerging interpretations reflected the lived experiences of the adolescents.

Ethical considerations

The study received ethical approval from the University of Technology Sydney Health and Medical Research Ethics Committee (ETH20-5255) and the Amhara Region Public Health Institution (No. H/R/T/T/D/3/887). Permission letters were also obtained from all CSHs involved in the study. ALHIVs aged between 15 and 18 provided their assent, and their legal guardians provided consent. A 19-year-old ALHIV provided verbal consent for their interview, which was conducted without their parent or legal guardian present. To protect the confidentiality of the interviews, any details that could identify individual participants were removed from the final transcripts, and all audio recordings were securely destroyed after transcription. Data collectors took necessary precautions during the COVID-19 pandemic, such as using hand sanitizer, wearing masks, and adhering to social distancing recommendations.

Results

Sociodemographic characteristics

A total of 12 adolescents living with HIV took part in this study. The interviewees had a mean age of 17.3 (SD = ±1.6). More than half of the participants were female (*n* = 7; 58.3%). Almost all interviewees had received a high school education (*n* = 11; 91.7%) through grades 9 and 10, while one participant had attended college. The median age at which the adolescents learned their HIV status was 9.5 years, with an interquartile range (IQR) of 7.25–11.0.

Thematic analysis

The analysis uncovered three themes (see Figure 1): The first concerned knowledge, misconceptions, and traditional cultural and religious beliefs about illness, HIV, and ART. The second centered on connection and belonging and the importance of finding support through community, family, and shared experiences with other

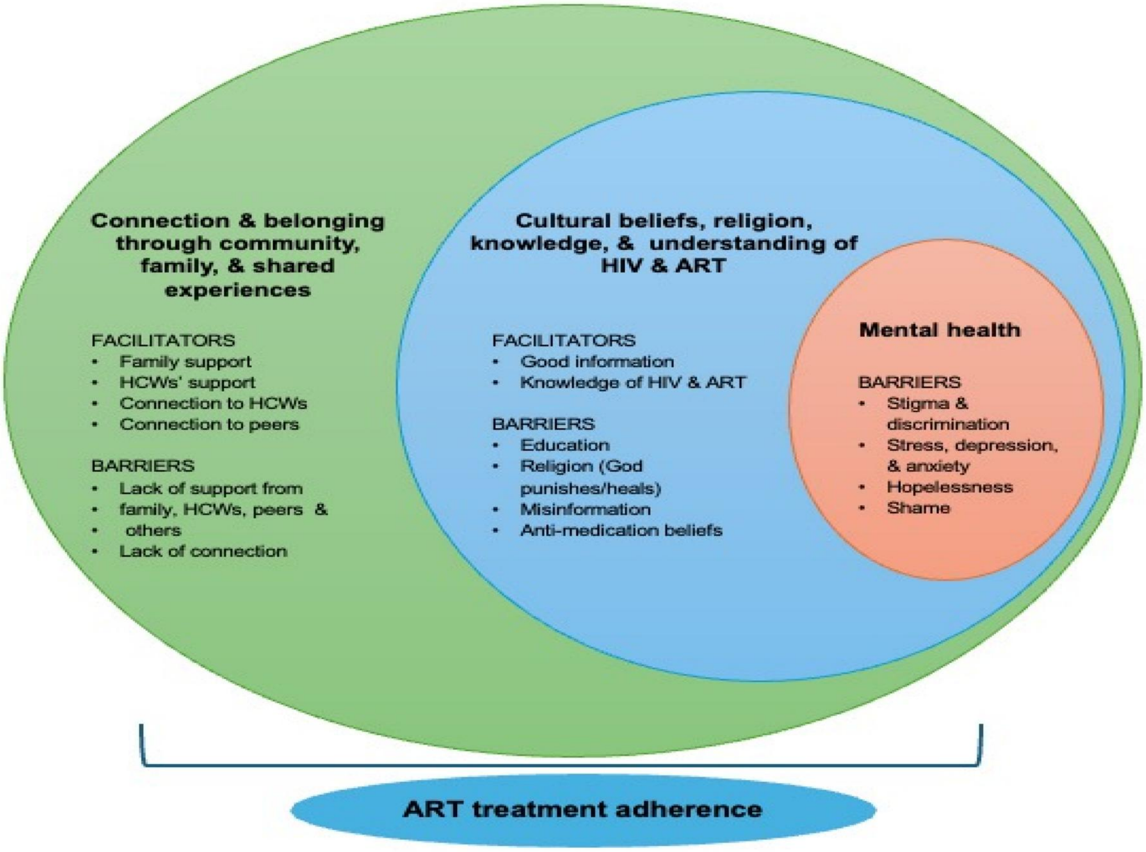

Figure 1. Conceptual framework of the facilitators and barriers to ART adherence in Ethiopian adolescents living with HIV.

ALHIV for maintaining adherence. The third focused on the stigma and isolation that many ALHIV experience and the resulting mental health challenges they face. Each theme and its sub-themes are discussed in the following sections.

Notably, thematic differences emerged across different adolescent age groups. Younger adolescents (15–16 years) more often emphasized fear of disclosure, misconceptions about treatment, and confusion surrounding long-term medication. In contrast, older adolescents (18–19 years) reflected more deeply on social identity, internalized stigma, and long-term hopelessness. These differences suggest that ART adherence challenges are developmentally shaped and call for age-tailored approaches.

Theme 1: Culture and religion: cultural/traditional knowledge and current understandings

Several participants ($n = 4$) highlighted the dual impact of cultural and religious beliefs on ART adherence, revealing both positive and negative influences. This theme encompassed three distinct sub-themes: religious perspectives (incorporating beliefs in divine punishment and healing by God), cultural beliefs regarding medication and the interplay of misinformation and educational factors.

Religion – "god punishes, and god heals"

Participants believed that illness comes from God and is intended to teach us a spiritual lesson. They expressed their belief in God's ability to heal them from any illness, and this belief was cited as a barrier to following treatment recommendations.

> I am the only person who lives with HIV. … God was cursing me. … I do not need to take the medications. [Participant 04, 17 years old, Female]

Others stated that if God caused the illness, then only God could cure it, making ART seem unnecessary:

> HIV/AIDS is a disease that God uses to punish people like me. This is because of our sin. I believe my God was cursing me. If he wants, he will heal me. [Participant 06, 19 years old, Male]

Cultural beliefs regarding medication, three participants

This sub-theme highlights how cultural beliefs shape attitudes toward modern medication, particularly ART, among participants and their parents. A common narrative was reluctance to take ART due to the belief that prolonged medication use could worsen illness rather than improve it. Daily medication was often associated with weakness, loss of autonomy, and a sense of "dehumanization," leading to feelings of detachment and stigma related to ART use.

> In our society, drug use is taboo. The ongoing follow-up for my long-term ART treatment often leaves me with a profound sense of diminished dignity, respect, and dehumanisation. [Participant 09, 17 years old, Female]

This negative perception of long-term medication uses frequently led to conflicts within families, which were difficult for adolescents to resolve. Some respondents said that family members had deep-held beliefs that ART medication was harmful and should not be taken. These differing beliefs about the appropriateness of ART led to breakdowns in communication, emotional tensions, and a lack of support for treatment. The familial disagreements were exacerbated by stressors such as financial difficulties. These beliefs and fears about medication and the disagreements between family members sometimes prevented hospital visits and ART refills.

> I am not very good at following the ART regimen that has been prescribed to me. A disagreement in my family caused me to miss some of my doses. On occasion, they did not let me go to the hospital to get my HIV medication refilled because they did not believe in antiretroviral therapy. [Participant 03, 19 years old, Female]

> Unfortunately, my family shares a discontentment with modern medicine. There are times when they discourage me from seeking a refill for my ART at the hospital, as they are resistant to accepting HIV medications. [Participant 11, 16 years old, Male]

Misconceptions, misinformation, and poor health education, three participants

Misconceptions and misinformation about antiretroviral medications were common in interview responses. Respondents believed that ART caused other illnesses, and this made them reluctant to adhere to an ART regime. The belief that ART medication causes cancer was a common misconception:

> Everyone, including myself, strongly dislikes people who use ART medications. The treatment is meant to be taken for a person's entire life, which may, in the long term, be harmful to users, such as [causing] cancer. [Participant 12, 15 years old, Male]

The belief that ART causes infertility was another common misconception. This was seen as either a cruel side-effect of ART or deliberate government intervention. ART was believed to be the cause of infertility by six out of the twelve interviewees.

> HIV medications [ART] affect human fertility. I see people who live with HIV and receive ART treatment have no children. I felt this medicine was to prevent a girl from giving birth; it comes with poison. I heard the government has a plan to avoid teenage pregnancy. Therefore, I am not interested in being known as an ART medication user. [Participant 03, 19 years old, Female]

> I thought HIV medication was incredibly cruel and believed it would have severe implications as if the drug had been used to stop a female from giving birth. During our peer meeting, we discussed how it prevents people from getting pregnant. [Participant 07, 19 years old, Female]

A lack of health education provided a scaffold for misinformation and an aversion to antiretroviral medications. Participants' responses indicated that health education on HIV/AIDS and its treatment was not widely accessible to adolescents and that counseling for ALHIV was often insufficient. The issues mentioned by participants included limited outreach programs, a lack of resources, a shortage of educational materials, and difficulties in providing effective counseling services to adolescents. This gap in accessible education and counseling on HIV/AIDS was stated to have a detrimental effect on medication adherence.

> I do not know much about HIV/AIDS and its medication, particularly treatment adherence. My friend was diagnosed with typhoid fever and took treatment for only seven days. So why do I take more medicine than this? Doctors did not assess my adherence as well as my treatment progress. Their counselling was insufficient. That is why I sometimes stop my treatment. [Participant 02, 15 years old, Female]

> I do not think about the importance of prescribing more than one pill for a single disease, HIV. When doctors provide me with more than one medication, I feel the problem is more severe and complicated in me, which causes me to feel depressed and hopeless and finally stop the medication. [Participant 11, 18 years old, Male]

Some participants felt strongly that services should disseminate HIV/AIDS and ART medication-related information to their families. Adolescents felt that education might help their families better understand HIV and the importance of treatment adherence.

> HIV intervention strategies do not involve the community, families, and people living with the virus. The health professionals did not counsel my family. The family must know my ART medications to support me. I am not comfortable with the content of the counselling service. It should include assessing information about my family status. [Participant 03, 19 years old, Female]

Education was seen as a way to counter negative cultural beliefs and misinformation about HIV and antiretroviral medication. Receiving education from their doctor or attending a workshop or conference on HIV greatly improved participants' ART adherence.

> Currently, HIV-related training, conferences, and experience sharing have helped me adhere to my ART treatment follow-up and comply with doctors' recommendations and advice. The health facilities and associations working on HIV/AIDS collaboratively organize training to increase the awareness of the people living with HIV. This exposed me to a lot of information on HIV, and I learned many things I should do as a person who lives with HIV. [Participant 10, 16 years old, Male]

Some participants felt that the knowledge they acquired about HIV and ART empowered them to the extent that they were now eager and prepared to offer assistance to others. This sense of readiness likely stemmed from the increased understanding of the challenges associated with HIV and the importance of adhering to ART. The participants might have developed a sense of responsibility and empathy, seeing an opportunity to share their knowledge and experiences to support others facing similar circumstances.

> Education and training about HIV are also very crucial in the fight against HIV. It helped me be consistent with my treatment to get better results. I am now in a position to guide and assist other people. [Participant 03, 19 years old, Female]

Theme 2: Connection and belonging: finding support through community, family, and shared experiences, three participants

Connection and support played a central role in facilitating ART adherence. Based on This theme encompasses four sub-themes: community support, familial relationships, healthcare provider connection, and peer support.

Community support: *"no one will help me" ….* three participants

Lack of financial, material, and social support from community and health services negatively affected ART adherence. Participants frequently stated that a lack of community support made it difficult to stick to the prescribed treatment regimen. Participants mentioned throughout interviews that they lacked financial support for personal needs and transportation to ART clinics. They felt that the needs of young people received low priority and that neither healthcare facilities nor other organizations were consistently assisting them with the social services they needed.

> I observed limited support from society. Society does not think of HIV as a national problem. No one will help me except for what I get from the hospital. But I always ask during our meetings, conferences, and discussions. [Participant 02, 15 years old, Female]

> The community does not give attention to us/children/adolescents. My thought [is that we do] not convince them like adults. They give attention to adults and those who have relatives in government or positions of power. [Participant 07, 19 years old, Female]

One adolescent observed that support for HIV was being pushed aside due to concerns about COVID-19. It was felt that healthcare resources, public awareness campaigns, and support services were being reallocated away from HIV-related initiatives to address the immediate and widespread impact of the COVID-19 pandemic resulting in less support.

> We, adolescents, have no voice in HIV service. Especially this time, everything has switched to COVID-19, and HIV has been forgotten; no one wants to hear you. HIV has a lower priority, and no one hears us, especially children and adolescents. So, we do not get enough food. We need money to keep our hygiene (especially during menstruation) and educational materials and clothes. [Participant 11, 19 years old, Female]

Some found support from organizations that hosted peer-to-peer events and conferences for adolescents living with HIV. In addition to increasing participants' knowledge and awareness of HIV and ART, and providing adherence support, some organizations helped with transport costs.

> "Receiving support from anyone lowers my stress and encourages me to take my medicine, which also drives me to think about the future. Associations working on HIV/AIDS support me in many ways, such as financial support for food and transport, organizing conference sessions to discuss HIV/AIDS and its treatment, and sharing experiences with our peers. This empowers me to follow the treatment strictly." [Participant 01, 16 years old, Female]

Familial support and the effect of parental conflict on adherence … three participants

Family members who had negative feelings about HIV or their child's medication tended to provide ALHIV little emotional support and this harmed adherence. Familial negative feelings were expressed as stigmatization, fear, and blame, which created a hostile and unsupportive environment. The negative impact of this lack of support on adherence was exacerbated by alcohol abuse in families, which impaired communication, caused financial instability, and heightened disagreements and emotional strain.

> My father negatively influenced me to stop taking ART and showing disrespect to me after he drunk. He pushed me to stop the treatment saying, "Why do you swallow this medication?" He said to me; you are healthy. His actions/behaviour discouraged me and pushed me not to take the medicines. He prevents me from going to the hospital on my appointment date. [Participant 12, 15 years old, Male]

Participants noted that conflicts arising between parents and conflicts involving the adolescents themselves acted as substantial barriers to adherence. The conflict created in the home environment characterized by stress and instability, disrupting mental and emotional well-being and making adherence to treatment regimens difficult.

> My parents (mother and father) always fight; they have no good relationship, which makes me nervous, anxious, and stressed. I decided to stop treatment because of this. (He put his head down). [Participant 06, 19 years old, Male]

Support from families helped adolescents cope with the effects of stigma and embrace their lives despite their HIV diagnosis. Adolescents frequently said that when they were diagnosed with HIV, they faced emotional distress, fear, and anxiety. Family support helped them through this difficult time by providing a safe and nurturing environment for them to express their feelings, ask questions, and seek reassurance, giving them a sense of emotional security. Support included encouraging adolescents to take medications, arranging times to attend HIV-related conferences, promoting financial independence, and collecting prescriptions on appointment days.

> In the absence of family, you're like a lone tree battling for survival. My mother is my everything, the foundation of my life. Her wisdom is delightful. Once, cradling me, she said, 'My beautiful girl, we are not accountable for others' actions, but we're responsible for our reactions. So, always be kind, and play with those who reciprocate. If not, remember, you're surrounded by countless angels who love and shield you.' This makes me resilient, not resentful toward those who judge my mom or me. Her approach has earned her immense respect in our village. [Participant 08, 18 years old, Female]

Healthcare professional connection to the client, three participants

Participants highlighted suboptimal treatment from HCWs as a significant impediment to medication adherence. Beyond issues of inadequate care, the challenges extended to disrespectful behavior, empathy gaps, deficient communication, and perceived neglect. Such negative encounters not only eroded trust but also instilled reluctance to follow medical advice, diminishing overall motivation for consistent medication adherence.

> Some medical professionals (doctors and nurses) handle/treat me inappropriately; they speak angrily and shout at me. … This demotivates me to adhere to the treatment. They do not want to know why I was absent during my appointment. When health professionals shout outside, someone may hear and know my status. People who live with the virus get embarrassed and may not monitor their treatment correctly. [Participant 08, 18 years old, Male]

Adherence was also impacted by HCWs failing to explain medications' advantages and side effects and not providing adequate time to evaluate and counsel patients.

> People who live with HIV need sufficient time to discuss it with their health professionals and other counselling groups. The health professionals or counsellors did not allocate enough time while discussing my problem; they immediately gave me the ART medications and let me go home. [Participant 12, 15 years old, Male]

Participants said that establishing a connection with supportive HCWs led to a shift toward a positive and constructive attitude toward treatment. This shift played a pivotal role in enhancing treatment adherence.

> Before I refilled my [ART] prescription, the healthcare providers gave me their advice. It was a big help in figuring out what I should do. It boosted my spirits and provided me with optimism and self-assurance. The health care provider's advice and counselling made it possible for me to forget all the limitations, including the social shame, the financial burden, and any other considerations that I believed were causes for not going to the hospital and taking the medications as directed. [Participant 04, 17 years old, Female]

A lack of peers and the pain of disconnection, three participants

The lack of connection with other ALHIV left respondents feeling alone and disconnected. Many families restricted their children's interactions with other children at ART clinics and during hospital visits, fearing that interaction would disclose their children's HIV status. Our respondents, due to limited contact with peers and restrictions imposed by their families, felt alone and separated from others, contributing to an overall feeling of disconnection from their social environment.

> I felt that I was the only person who lived with HIV. Questions like why should I take ART medication and no one else should? Frequently. I ask myself, "Why should I live?" There are many questions in this regard. I could not see any adolescents and children visiting the hospital; this significantly overwhelmed me. … I thought I was the only one and should stop taking the medications. [Participant 10, 16 years old, Male]

> My father was always very concerned that my classmates and neighbours would know that I had HIV if I interacted with them, so he warned me not to play with them, go to their houses, or talk to them. [Participant 03, 19 years old, Female]

The importance of shared lived experience, three participants

Connection with peers positively impacted ART adherence and improved ALHIV's outlook on their health. Once the connection with peers was established, adolescents felt a sense of relief and acceptance, developed new friendships, and were more likely to visit the health facility. Peer support was an essential facilitator of medication adherence.

> Before I met peers of the same age living with the virus, life was meaningless for me. Peers are good for me. We share experiences, plan our futures, encourage each other, and listen to each other. HIV-negative people sometimes did not feel my pain like those living with the virus. [Participant 12, 15 years old, Male]

> I am excited to meet my friends and look forward to my appointment. Occasionally, we plan to do something together for our next hospital visit. We miss each other. The common goals we share, the fruitful discussions we have at the hospital, and the sharing of our day-to-day experiences motivate us to visit the hospital on the appointment day. [Participant 09, 17 years old, Female]

Theme 3: Stigma and mental health challenges affecting adherence, three participants

Poor mental health stemming from experienced, anticipated, and internalized stigma emerged as a significant barrier to treatment adherence. Participants reported experiencing depressive symptoms, feelings of hopelessness and anxiety, and an overarching sense of shame. They reported both anticipating stigmatization by their community and experiencing stigmatization and discrimination that left them feeling profoundly isolated. These psychological challenges collectively hindered consistent adherence to prescribed treatment regimens.

An aching sense of depression, anxiety, and hopelessness

Participants described an aching sense of depression, anxiety, and hopelessness that profoundly and directly influenced treatment adherence. The chronic nature of HIV, combined with the stigma and societal challenges related to the infection, created a heavy emotional and psychological burden and the fear of disclosure and its potential social consequences added a layer of anxiety and stress.

> HIV medication has more adverse effects on me, including stress and anxiety. In addition to the above medical conditions, I have also experienced depression and become hopeless in my future life. [Participant 02, 15 years old, Female]

> When thinking of ART medication, I always feel hopeless or helpless. When I take HIV medication, my stress and anxiety increase, and I cannot sleep. [Participant 03, 19 years old, Female]

> I feel hopeless … my stepmother mistreats me due to my status. I felt angry, anxious, sad, and desperate and decided to stop the treatment. [Participant 05, 19 years old, Female]

Anticipated stigmatization and the pain of "degrading, dehumanizing" remarks

The study uncovered intense anticipated stigma among participants. Most strongly believed that their community or family would hold negative opinions about them if their HIV status were disclosed and feared potential gossip, mockery, and laughter from extended family, friends, and community members. This apprehension was grounded in painful concrete experiences of stigmatization and discrimination. Stigma affected care in two ways. First, the fear of disclosure sometimes resulted in missing medication doses as respondents felt they could not take medication openly in front of others. Second, participants believed that having a mental illness or seeking therapy would be perceived as a sign of weakness and this apprehension led them to avoid seeking help for their mental health challenges due to this stigma.

> People who know you have AIDS do not want to come close to you as if you are a horrific thing. You cannot feel free. Wherever you go, they start talking, 'See that one, she is sick.' [Participant 07, 19 years old, Female]

> I often hear my friends speak negatively about people being HIV-positive. They always have degrading, dehumanising, or negative remarks about me because of my HIV status. I do not take my medications in front of them or whenever I go out, or they come over to visit me. [Participant 08, 19 years old, Male]

Adolescents in the study frequently engaged in cross-district travel to access ART in order to minimize potential disclosure of their HIV status within local communities and reduce the judgment and discrimination they felt disclosure would entail. By strategically traveling for treatment, adolescents sought to safeguard their privacy and shield themselves from social consequences linked to receiving ART.

> The fear of stigma is one of the difficulties. I want to get ART medicine from a different area where I cannot find anyone who knows me. [Participant 10, 16 years old, Male]

Internalized stigma and shame: "a disgusting thing"

In addition to experiencing stigma and anticipating it from others, many participants also internalized stigma, reporting feeling a profound sense of shame about their status. Shame was related to being "seen around the HIV clinic" to collect medication for a disease that can be sexually transmitted.

> After I knew my status, my thoughts, and behaviour would continue to be deeply affected by fear and shame. I did not feel well. Despite having open, loving, compassionate family and friends around me, I did not feel comfortable disclosing my diagnosis and ART follow-up. [Participant 10, 16 years old, Male]

> Before disclosing my HIV status to others, I repeatedly went back home without taking my prescriptions [ART], especially when I saw people who knew me around the ART clinic. I then stopped taking my medicine until my next appointment. [Participant 02, 15 years old, Female]

> Living with HIV feels like carrying a hidden burden. 'I sometimes think of myself as a disgusting thing because of how people talk about HIV.' This internalized stigma creates a deep sense of shame and isolation, making it difficult for young people to fully engage with their treatment and society. [Participant 08, 19 years old, Male]

Discussion

This exploratory qualitative study examined adolescents' experiences receiving ART and investigated facilitators and barriers to ART adherence. To the best of our knowledge, this is the first qualitative study examining the factors that affect treatment adherence among ALHIV in Ethiopia.

Our study found three overarching themes regarding ART treatment adherence. The first theme centered on knowledge and education, which operated at the individual and community levels. It concerned findings of a cultural understanding of medication and illness in which long-term medication was distrusted, long-term illness was seen as the work of the divine, and misinformation about HIV/AIDS and ART was prevalent. The second theme concerned connection and belonging and the social, and clinical, and material support this entailed. The impact of support was felt at the interpersonal, organizational, and community levels. The third theme identified was poor mental health, characterized by stress, depression, anxiety, hopelessness, and shame. These mental health challenges were primarily driven by internalized self-stigma and the anticipated stigma from the community, as well as experienced stigma and discrimination. Poor mental health was an individual-level impact of stigma occurring at all levels of society.

Adolescents in central Ethiopia are embedded within tightly knit social structures where religious authority, family decisions, and community norms heavily influence health behavior. Despite their age, many adolescents do not exercise full autonomy over their health decisions, and cultural narratives such as associating illness with divine punishment or viewing chronic medication with suspicion—are prevalent even among well-informed youth. This social environment, coupled with developmental vulnerabilities, significantly shapes their ART adherence experiences.

Theme 1: Cultural beliefs, religion, knowledge, and understanding of HIV and ART

Our qualitative analysis highlighted the profound influence of cultural beliefs and religious teachings on long-term HIV medication adherence in Ethiopia. Some adolescents perceived HIV as a punishment from God, leading to challenges in accepting and adhering to ART, while others viewed ART as a means through which God can heal them, motivating adherence. Cultural understandings of long-term medication use as inappropriate, particularly among parents, also emerged as a barrier to adherence.

Religion and culture

The importance of religious beliefs in shaping adherence behavior is not entirely surprising. Ethiopia is a profoundly religious country where faith plays a central role in everyday life. According to national surveys, the majority of Ethiopians identify as Ethiopian Orthodox Christians, followed by Muslims and Protestants, with regional variations in dominance. Religion is not merely a personal practice but a cornerstone of communal identity, with nearly all individuals attending religious services monthly and over 90% engaging in daily prayer. ART (Finke et al., 1999). These shared beliefs often influence perceptions of illness, healing, and moral responsibility, including views that HIV is a divine punishment or that healing is dependent on spiritual intervention. Such beliefs can significantly affect adolescents' willingness to adhere to ART. Belief in the curative powers of holy water and the reliance on traditional medicine is deeply embedded in Ethiopian culture, and the coexistence of these traditional beliefs alongside modern medicine creates a rich array of healthcare perspectives that continue to influence health-seeking behavior in the country (Tymejczyk et al., 2016). Research in numerous settings has demonstrated that cultural and religious beliefs play a significant role in influencing adherence in individuals facing chronic illnesses like HIV/AIDS (Azia et al., 2023; Hatah et al., 2015; Wahab et al., 2021). Other qualitative studies of ART adherence among adolescents have also identified themes around the impact of religious beliefs on adherence (Azia et al., 2023; Fleischer & Avery, 2020). Our findings and previous studies suggest that religious beliefs can both hinder and facilitate adolescents' attitudes and behaviors regarding ART. Example: Many religious teachings emphasize caring for one's health, respecting the body, and seeking medical care when needed. Religious leaders and communities can promote ART adherence by framing it as a moral duty to maintain one's health and protect others from infection.

Cultural resistance to medication has been found to be a complex phenomenon rooted in cultural norms about illness, values, and Western medicine that significantly influences adherence to ART in adults and adolescents (Koroka, 2021; Robbins et al., 2012). At least one previous study in Ethiopia has noted that a notable minority of patients express a cultural distrust of medication, perceiving it as fundamentally harmful and addictive (Kasahun et al., 2022). This disbelief has been associated with suboptimal adherence, highlighting the tangible impact of cultural perspectives on healthcare practices (Kasahun et al., 2022).

While the strong influence of religious and traditional cultural understandings of illness, health, and medication might have been expected among older people living with HIV in Ethiopia, it is noteworthy that even among the young, relatively well-educated youth (compared to national averages) in our sample, these beliefs persist and are compounded by parental and community beliefs. Our findings underscore the importance of having a nuanced, culturally sensitive understanding of illness and good health when designing HIV health education and stigma reduction material for patients, their families, and their communities.

Misinformation and education

We found that misinformation or a lack of information regarding HIV and ART serves as a substantial barrier to treatment adherence. This finding reaffirms the literature documenting significant negative associations between being misinformed or poorly informed about HIV/AIDS and ART and poor ART adherence (Dowse et al., 2014; Galea et al., 2018; Gilling-Smith et al., 2006) and the well-established understanding of the importance of health education in promoting adherence to HIV treatment (Malcolm et al., 2003).

The misconception found in our study regarding an association between ART and infertility has been observed in other studies of HIV in sub-Saharan Africa. The pervasiveness of this misconception could be due to insufficient counseling by health professionals and also a social media environment in which accurate, youth-friendly information is scarce, while misinformation from peers is abundant (Vukapi, 2020). Misconceptions about the impact of medication on fertility may be particularly powerful for adolescents who have not yet had children and addressing them should be a priority for adherence education initiatives in this population.

In our study, ALHIV reports that exposure to HIV/AIDS training and conferences helps support adherence. Studies have consistently reported the importance of HIV-related knowledge for improving ART adherence (Galea et al., 2018; Hornschuh et al., 2017) and highlighted counseling as an essential component of comprehensive HIV/AIDS programs (Chippindale & French, 2001) as counseling provides opportunities to understand and address patients' needs, increase patients' understanding of the diseases, and build trust and a rapport between patients and providers.

This study was guided by the socio-ecological framework, which enabled exploration of adherence factors across multiple levels—from individual beliefs and family dynamics to community stigma and healthcare system interactions. This framework was particularly well-suited to understanding the layered and interrelated nature of barriers and facilitators to ART adherence among adolescents in the Ethiopian context.

Theme 2: Support from community, family, peers, and HCWs affects ART adherence

Community and familial support

Study participants highlighted the critical role of community, family, and peer support in promoting adherence and found a lack of support from social networks to be a significant barrier. This finding is in line with existing literature which has found that the presence of support from others—such as family, friends/peers, organizations, and health professionals—leads to better ART adherence in adults and adolescents (Ahmed et al., 2021; Audi et al., 2021; Bangsberg et al., 2006; Bezabhe et al., 2014; Byakika-Tusiime et al., 2005; Cluver et al., 2016; Kuznetsova et al., 2016; Mao et al., 2018; WHO, 2013). External support to facilitate health monitoring, share information, and provide a sense of security and care may be particularly important for ALHIV who would struggle to support themselves independently. A particularly poignant thread in participants' discussion of familial support was the stress and conflict within families due in part to the diagnosis which made adherence challenging

HWC support

In addition to support from the community and family, support from and connection to HCWs was found to be an important factor in adherence. Many of our respondents felt that providers were disrespectful and that the counseling they received was inadequate and rushed, providing them with insufficient information to achieve adherence. The deleterious effect of disrespectful care and poor provider communication on patient understanding, trust in the health system, medication adherence, and utilization of care is increasingly recognized (Sabaté, 2003). Communication and collaboration barriers among clinical staff have been identified as a significant threat to enhancing healthcare safety and quality (Hughes, 2008). Our findings corroborate this growing concern and are in line with the wealth of empirical studies that have shown that counseling and supportive and interested healthcare professionals aid patients in taking their HIV medication consistently (Janini et al., 1998; Lewis et al., 2006; Nabukeera-Barungi et al., 2015; Wasti et al., 2012).

Material support

Adolescents in this study identified material support, particularly access to healthy food and transportation, as important factors influencing adherence. This aligns with findings from previous studies in sub-Saharan Africa that identified food and transportation as substantial barriers for families with members receiving ART (Audi et al., 2021; Bangsberg et al., 2006; Byakika-Tusiime et al., 2005). Importantly, our findings parallel those observed in studies within adult populations, emphasizing the universal significance of support structures in optimizing treatment outcomes (Abdulai et al., 2022; Bezabhe et al., 2014)

Theme 3: Stigma and mental health

Adolescents' developmental stage compounds these challenges. During this critical period of identity formation, they are particularly sensitive to peer judgment, struggle with autonomy in decision-making, and experience heightened emotional responses to stigma, rejection, and illness. These developmental traits make them especially vulnerable to mental health distress and poor adherence outcomes, reinforcing the need for age-appropriate, developmentally tailored interventions.

Stigma

Stigma was a thread that ran through all themes: it emerged out of poor knowledge and cultural understandings of ill health as God's punishment; fueled poor communication in health care and lack of support in the home and community; and drove the intense feelings of shame, fear, and despair that led to mental illness, lack of disclosure, and poor adherence.

Stigma and discrimination surrounding HIV/AIDS affected individuals' willingness to disclose and openly discuss their condition, and this, in turn, made adherence difficult. The connection between HIV-related stigma, discrimination, and treatment adherence is well-established, as indicated by a comprehensive systematic review and meta-analysis (Katz et al., 2013) as well as a range of qualitative studies (Audi et al., 2021; Bezabhe et al., 2014; Enane et al., 2020; Mavhu et al., 2013; van Wyk & Davids, 2019; Wanjala et al., 2023). As in our study, decades of research have found that stigma reduces disclosure (Makin et al., 2008; Olley et al., 2016; Smith et al., 2008; Tsai et al., 2013), and lack of disclosure has been found to be an impediment to treatment adherence (Mengesha et al., 2023). Overall, stigma and discrimination, deeply entrenched in societal attitudes about illness and medicine, emerge as formidable barriers shaping ALHIV's commitment to their HIV treatment regimen both in our study and elsewhere (Ahmed et al., 2021; Mshana et al., 2006; Rahangdale et al., 2010).

Poor metal health

Given the stigma, fear of disclosure, and feelings of shame and isolation reported by our respondents, it is not surprising that we also found that they had a history of mental health issues such as stress, depression, and anxiety, which impacted treatment adherence. Anxiety and depression have frequently been described as important factors in HIV medication adherence (Uthman et al., 2014), and they are common psychiatric disorders among PLHIV (Bing et al., 2001). Our results aligned with other studies which showed that treatment adherence and depression were negatively related (Magnezi et al., 2014; Truong et al., 2021) including studies in adult populations, underscoring the continuity of these challenges across different age groups (Bezabhe et al., 2014). The relationship between anxiety and adherence has been argued to be due to anxiety increasing fear of side effects, inhibiting support-seeking efforts, and increasing the risk that PLHIV will develop inadequate coping mechanisms (Brandt et al., 2017).

In addition to anxiety, respondents spoke of experiences of loneliness stemming from the apprehension of societal judgment and ostracization, which compounded their emotional challenges. A pervasive sense of hopelessness permeated their psychological landscape, potentially decreasing their motivation for continuing to adhere to their treatment regimen. These experiences have been reported in previous studies on adherence in sub-Saharan Africa (Albassam et al., 2017; Awiti Ujiji et al., 2011; Do et al., 2010; Duff et al., 2010; Ramadhani et al., 2007).

Shame

Our findings underscore the pivotal role of internalized self-stigma as a mental health and adherence challenge. Internalized stigma manifested as shame—a nuanced emotion interwoven with cultural and religious constructs—which influenced ALHIV's motivation and self-concept, subsequently impacting their adherence to ART. The impact of shame on hindering treatment adherence was highlighted in earlier studies, where it led to practices such as skipping antiretroviral medication doses (Lyons & Dolezal, 2017). Shame has been found to trigger a compulsion to conceal both its source and the associated emotion, contributing to this observed link with suboptimal adherence (Lyons & Dolezal, 2017; Mendible, 2016).

Developmental variation and divergent narratives

Our findings indicate that challenges to ART adherence varied across different age groups. Younger adolescents (15–16 years) frequently expressed fears around disclosure, confusion about the need for long-term medication, and a strong influence of parental beliefs. In contrast, older adolescents (18–19 years) more often reflected on issues related to social identity, internalized stigma, and a sense of long-term hopelessness. These differences underscore the need for age-specific, developmentally appropriate interventions tailored to the distinct challenges faced at different stages of adolescence. This finding is supported by previous research, which has also shown that barriers to ART adherence among adolescents differ by age, with younger adolescents more influenced by caregivers and developmental understanding, while older adolescents face more complex psychosocial challenges such as identity formation, stigma, and mental health issues (Ghidei et al., 2013; Shubber et al., 2016).

Study implications

In this qualitative analysis, we highlighted the complex landscape of ART adherence in adolescents, emphasizing the prevalence of poor mental health driven by stigma and isolation as a formidable barrier to ongoing care. Our findings support calls for routine mental health screening and care to be incorporated into HIV care for ALHIV. While we acknowledge the complexity and resource demands that adding routine screening would entail, the intensity of the mental health challenges recounted suggests that addressing co-occurring mental health issues, including substance abuse, is crucial for advancing Ethiopia's ART programs. Further research is warranted to improve our understanding of the behavioral health challenges among Ethiopian ALHIVs as well as appropriate care initiatives.

A key finding was that parental attitudes toward HIV/AIDS and ART were a major barrier to ART adherence for some ALHIV. These findings indicate the usefulness of culturally sensitive and intensive family-oriented therapy, health education and peer support for parents and caregivers. Family support initiatives, perhaps involving other community members as well, may be pivotal in helping ALHIV remain mentally and physically healthy. Psycho-social support should be complemented with material support as financial hardships due to treatment emerged as both a barrier to adherence and a source of familial conflict. Initiatives ensuring access to nutritious food and reliable transportation that involve the community, civic organizations, and the government could contribute to improved well-being and treatment adherence, empowering ALHIV in their ongoing care.

Recognizing the profound impact of cultural beliefs and religious teachings on stigma, mental health and HIV medication adherence means significantly scaling up rigorous, culturally sensitive health education and stigma reduction activities informed by local priorities and understandings of health and anchored by community stakeholders. Within healthcare facilities, quality improvement initiatives should focus on enhancing provider-patient interactions, integrating psychosocial support and early mental health interventions for ALHIV. Continued efforts to implement patient-centered healthcare, reduce communication barriers, and foster professional development in Ethiopia's health system are crucial for improving uptake and adherence in HIV treatment programs. Ongoing research into appropriate stigma reduction campaigns and the performance of comprehensive policies are needed to develop adaptive strategies and promote a supportive environment for optimal adherence and enhanced healthcare quality. Continued study of ART adherence should remain a priority because adherence is a dynamic phenomenon whose influences change over time particularly in rapidly growing low and middle-income countries such as Ethiopia (Biadgilign et al., 2009; Vervoort et al., 2007).

Study strengths and limitations

A notable strength of this qualitative study is its ability to identify policy intervention areas for HIV programming in Ethiopia. Another strength is its inclusion of participants from a large geographic area which allowed us to capture diverse perspectives and experiences, contributing to a more comprehensive understanding of ART adherence among Ethiopia's youth than previously found.

Although the study provides original insights into potential areas of improvement in the care provision for ALHIV in Ethiopia, it has important limitations. The first is that it only collects data from patients. We might have obtained a richer understanding of adherence challenges among ALHIV if parental, community, and health professionals' perspectives were also captured and the data triangulated. Additionally, our study might not accurately represent the perspectives of those who have dropped out of care or who are not receiving care at public hospitals. Our study was unable to capture the important perspectives of adolescents who had stopped receiving care and their adherence issues may have been overlooked.

Conclusions

This study highlights the complex interplay of of cultural beliefs, social support, and psychological well-being in shaping ART adherence among Ethiopian adolescents living with HIV. Misconceptions about antiretroviral therapy, religious interpretations of illness, and limited health education contribute to treatment resistance, while family support from peers, and supportive healthcare providers facilitates adherence. Stigma, whether anticipated, experienced, or internalized emerged as a major barrier, often resulting in distress, secrecy, and missed doses.

To address these challenges, we recommend implementing a set of context-specific interventions. These include culturally sensitive health education campaigns that involve religious and community leaders to counter misinformation; establishment of peer-led support groups and adolescent-friendly clinics to create safe, stigma-free spaces; integration of mental health screening and counseling services into HIV care; and provider training to ensure nonjudgmental, adolescent-centered service delivery. Implementing these strategies will require health system strengthening through dedicated funding for adolescent HIV services, improved coordination across sectors (including education and religious institutions), and decentralization of care to improve accessibility. A more explicit investment in adolescent-centered models of care will not only enhance ART adherence but also promote resilience, engagement, and long-term health outcomes for adolescents living with HIV.

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