Student's Journal of Health Research Africa
e-ISSN: 2709-9997, p-ISSN: 3006-1059
Vol.6 No. 9 (2025): September 2025 Issue
https://doi.org/10.51168/sjhrafrica.v6i9.2009
Original Article

Hiv/aids treatment adherence among adolescents attending Mildmay Hospital, Uganda, Wakiso District. A cross-sectional study.

Elly Tabaaro, Habert Mpamize, Immaculate Naggulu Prosperia, Jane Frank Nalubega*
Mildmay Institute of Health Sciences

ABSTRACT

Background

Globally, over 39 million people were living with HIV in 2023, with adolescents accounting for a significant portion of new infections and deaths. In Uganda, the non-adherence rate to ART among adolescents is 48.7% attributed to stigma and medication side effects. The purpose of the study was to assess factors affecting adherence to HIV/AIDS treatment among adolescents attending Mildmay Hospital, Uganda, Wakiso District.

Methods

A descriptive cross-sectional study design was used, employing quantitative methods of data collection, conducted in Mildmay Hospital, Uganda, Wakiso District. The data collected was analysed manually, and after the findings were entered into a Microsoft Excel 2013, which was then presented in the form of tables, pie-charts, and graphs.

Results

out of 52 respondents, results showed that 100% of the respondents reported taking their medication daily, yet 73% experienced stigma, 77% had difficulty swallowing tablets, and 33% failed to return for refills. Socio-demographic data indicated that 36% were aged 19 years and above, 40% were in secondary school, and 58% were currently attending school. Regarding hospital-related factors, 52% reported unfair treatment by health workers, 58% lived over 10 km from the facility, 42% missed treatment due to stockouts, and 69% faced long waiting times. Drug-related factors included 46% having difficulties swallowing drugs, 43% experiencing side effects, 79% citing the long duration of treatment as a challenge, and 62% expressing doubts about medication effectiveness.

Conclusion

Adherence to HIV/AIDS treatment among adolescents was influenced by stigma, difficulty swallowing medication, long treatment duration, negative experiences with health workers, and long distances to health facilities.

Recommendation

Adolescent-friendly services, improved drug availability, supportive healthcare interactions, community sensitisation, and enhanced access to nearby treatment facilities are recommended to improve adherence to HIV/AIDS treatment.

Keywords: *Factors Adherence to HIV/AIDS treatment, Adolescents attending Mildmay Hospital.*
Submitted: *2025-06-17* ***Accepted:*** *2025-08-27* ***Published:*** *2025-09-15*

Corresponding Author: Jane Frank Nalubega
Email: janecll.nalubega@gmail.com
Mildmay Institute of Health Sciences

Background

Human Immunodeficiency Virus (HIV) is a virus that attacks the immune system, specifically the CD4 cells (T cells), which help the body fight off infections (Iqbal et al., 2024). Without treatment, HIV can progress to acquired immunodeficiency syndrome (AIDS), a condition where the immune system is severely compromised (Bai et al., 2020). Adolescents living with HIV are a particularly vulnerable group due to the unique challenges they face in adhering to treatment (Yusuf & Agwu, 2021). While ART is highly effective in improving the quality of life and reducing mortality rates, treatment adherence is crucial for its success (Buh A.W. et al., 2023). Globally, over 39 million people

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were living with HIV in 2023, with adolescents accounting for a significant portion of new infections and deaths (Payagala & Pozniak, 2024). In Africa, where 66% of global HIV cases are reported, non-adherence to ART among adolescents is alarmingly high (Olashore et al., 2021). In South Africa, results reported non-adherence rates of 74% with reasons including lack of support, stigma, and fear of disclosure (Nice, 2023). Other studies in Nigeria have identified socioeconomic barriers, side effects of medications, and inadequate healthcare systems as critical factors contributing to low adherence (Macquart de Terline et al., 2019). In East Africa, specifically Kenya, about 1.4 million people live with HIV, with adolescents making up a significant portion (Govender & Poku, 2024). Non-adherence to ART among adolescents is reported at 58.2% due to factors such as lack of family support, stigma, and lack of awareness about the importance of treatment adherence (Ngige & Ndayala, 2020). Despite the availability of free ART services through government and non-governmental organisations, adherence among adolescents remains alarmingly low (Flämig et al., 2019). In Wakiso District, Annual District records of 2024 indicate that 39.6% of adolescents on ART exhibit poor adherence, with the most affected being those aged 10–19 years (Buh A.W., 2024). Addressing these barriers is crucial for improving the health outcomes of adolescents living with HIV. Understanding these factors will help inform targeted interventions to improve adherence and reduce the burden of HIV/AIDS. The study aims to assess the factors affecting adherence to HIV/AIDS treatment among adolescents attending Mildmay Hospital, Uganda, Wakiso District, to provide insights that stakeholders can use to improve adherence and reduce the negative health outcomes associated with non-adherence.

Specific Objectives

The study was carried out with the following objectives;

1. To determine the individual factors affecting adherence to HIV/AIDS treatment among adolescents attending Mildmay Hospital, Uganda, Wakiso District.
2. To establish the hospital-related factors affecting adherence to HIV/AIDS treatment among adolescents attending Mildmay Hospital, Uganda, Wakiso District.
3. To identify the drug-related factors affecting adherence to HIV/AIDS treatment among adolescents attending Mildmay Hospital, Uganda, Wakiso District.

METHODOLOGY

Study Design and Rationale

A descriptive cross-sectional study design employing a quantitative research method to obtain data. Descriptive methods were used because they assessed the factors of the topic and analyzed the data using descriptive statistics. A cross-sectional design was chosen because it was carried out at one point in time without further follow-up. The design was selected because it was cost-saving, easier to carry out, and could be completed in a shorter time.

Study Setting and Rationale

A study at Mildmay Hospital, Uganda, located in Wakiso District, Central Uganda. The hospital is situated approximately 12 kilometers southwest of Kampala City, along Entebbe Road. It is a private not-for-profit healthcare facility owned and operated by Mildmay Uganda, a faith-based organization. The hospital is strategically located to serve Wakiso District and its 16 neighboring districts, including Kampala, Mpigi, Mukono, and Entebbe. Mildmay Hospital Uganda has over 100 beds, including a 33-bed capacity children's ward (Elizabeth Ward) for critically and terminally ill children aged 0-18 years. Mildmay Hospital in Uganda has over 500 active ART patients, of which a significant proportion are adolescents. Mildmay Hospital serves as a center of excellence for the management of HIV/AIDS and provides a wide range of healthcare services, including antiretroviral therapy (ART), HIV counseling and testing, prevention of mother-to-child transmission (PMTCT), pediatric HIV care, psychosocial support, and offers outpatient and inpatient services by general practitioners and specialists. The hospital was selected for this study due to its reputation as a leading institution in HIV care. It's adolescent-focused programs and the large volume of young HIV-positive patients accessing its services. The geographical coordinates of Mildmay Hospital, Uganda, are approximately 00°15′30″N, 32°31′10″E.

Study Population

The study population consisted of adolescents aged 13-19 years with HIV/AIDS attending Mildmay Hospital, Wakiso District during the time of study.

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Sample Size Determination

The sample size determination followed the guidelines provided by Krejcie and Morgan's table of 1970. According to Mildmay Hospital records in 2024, there were approximately 60 HIV-positive adolescents who did not adhere to HIV/AIDS treatment. Based on this available population, Krejcie and Morgan's table provides an appropriate sample size, with the findings being representative of the entire population. Therefore, the researcher considered N to be 60 and S to be 52 as indicated in Table III in the appendix section.

Sampling Procedure

A simple random sampling technique was used, with study respondents selected from the ART clinic register. To obtain the study sample size, the researcher prepared 60 papers, with 52 labeled "P" and the remaining 8 left blank. All the papers were placed in a single box, and caretakers or adolescents were asked to pick one paper without replacement. The respondents who picked the 52 papers labeled "P" participated in the study. This process of picking a single paper took five days, with 11 respondents sampled each day of data collection until a total of 52 respondents was reached for the success of the study.

Selection Criteria

Inclusion Criteria

The study included all adolescents aged 13-19years who, upon informed consent, agreed to participate in the study.
Those in a healthy situation who could afford to respond to the questions aged 13-19years

Exclusion Criteria

An adolescent who, upon informed consent, failed to participate
Those in an unhealthy situation who could not afford a response
Adolescents below 13years and 19years above did not participate in the research study.

Dependent Variables

These are the characteristics of the study that a researcher cannot control to cause change. In this case, this was the adherence to HIV/AIDS treatment, which meant the extent to which a patient consistently followed the prescribed HIV/AIDS treatment medication by healthcare providers.

Independent Variables

This is a characteristic of the study that a researcher can manipulate in order to bring change. In this case, these included;
Individual-related factors meant hindrances to HIV/AIDS treatment among HIV-positive adolescents due to individual-related causes.
Health facility-related factors meant hindrances to adherence to HIV/AIDS treatment among HIV-positive adolescents due to health facility-related causes.
Drug-related factors meant hindrances to adherence to HIV/AIDS treatment among HIV-positive adolescents due to medication-related causes.

Research Instruments.

A structured questionnaire consisting of four sections was used. Section A covered socio-demographic data, Section B focused on individual factors, Section C addressed health facility-related factors, and Section D explored drug-related factors. Each section contained closed-ended questions to assess adolescents' responses objectively. However, illiterate respondents were also considered, as the questions were verbally read to them while the researcher filled in their views.

Data Collection Procedure

After the approval of the research proposal by the supervisor and the institution's Research Committee (IRC), an introductory letter with authorization from the Principal of Mildmay Uganda School of Nursing and Midwifery was provided to the researcher. This letter was presented to the administration of Mildmay Hospital to seek permission to carry out the study among adolescents. Data collection involved using a structured questionnaire for adolescents with HIV/AIDS at the ART clinic. The process also included training research assistants who helped translate English questions into local languages for illiterate respondents during data collection. Data was collected by sampling 11 participants over five days to achieve the sample size of 52 respondents, ensuring the success of the study.

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Data Management

After each day's data collection, the completed questionnaires were checked for completeness and coded. The questionnaires were then stored in secure files within a lockable box, with the keys kept safely. Electronic data was managed with a computer password to ensure confidentiality and allow for future reference of the findings.

Data Analysis

Data was first tallied manually and then entered into Microsoft Excel (version 2013) for analysis. Descriptive statistics were used, and the results were presented in figures, pie charts, graphs, and tables to establish the accuracy of the study findings. Interpretation was then done based on the analysis.

Quality Assurance

Validity

This was ensured by setting questions according to the research objectives and working with the supervisor to ensure that the tool had both face and construct validity.

Reliability

The questionnaires were pre-tested at Entebbe Regional Referral Hospital among 12 selected respondents, and necessary corrections were made. They were then re-tested among 3 respondents to make final adjustments before the formal study.

Ethical Considerations

After the approval of the research proposal by the supervisor and the institution's Research Committee (IRC), an introductory letter with authorization from the Principal of Mildmay Uganda School of Nursing and Midwifery was given to me, which I presented to the administration of Mildmay Hospital to seek permission to carry out the study among the adolescents who could consent on their own. The director directed me to the person in charge of the ART department, where I introduced myself to the person in charge and was allowed to interact with the respondents. The self-introduction and purpose of the study were explained to each respondent by me. Written consent and assent were obtained from the adolescents. I ensured confidentiality by using numeric codes instead of names, and participants were free to withdraw at any time.

RESULTS

Social demographic characteristics

Table 1: Social demographic characteristics of the respondents, N=52

Variable	Category	Frequency(f)	Percentage (%)
Age	13-15 years	16	31
	16-18 years	17	33
	19 years and above	19	36
Level of education	Not applicable	7	14
	Primary level	13	25
	Secondary level	21	40
	Tertiary level	11	21
Currently attending school	Yes	30	58
	No	22	42
Occupation of caretaker	Casual worker	23	44
	Employed	16	31
	Self-employed	8	15
	Unemployed	5	10

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Table 1, majority of the respondents, 19(36%) were 19 years and above, 17(33%) were 16-18 years, while the minority, 16(31%) were 13-15 years. Most of the respondents, 21(40%) were in secondary school, 13(25%) were of primary education, 11(21%) were of tertiary education, while the least, 7(14%) were having no education background. Most of the respondents, 30(58%) attending school, and the least, 22(42%) were not attending school. Majority of respondents, 23(44%) mentioned that their caretakers were casual laborers, 16(31%) mentioned that they were employed, 8(15%) were self-employed, while minority, 5(10%) were unemployed.

Individual Factors Affecting Adherence to HIV/AIDS Treatment among Adolescents Attending Mildmay Hospital, Uganda, Wakiso District

Table 2 shows how often respondents take their HIV/AIDS medication. N=52

Variable	Frequency (f)	Percentage (%)
Daily	52	100
Every two days	0	0
Every three days	0	0
I am unsure	0	0
How often respondents were stigmatized because of taking HIV/AIDS medications		
Many times	38	73
Some times	14	27
Never	0	0
Whether respondents find it easy to swallow the HIV/AIDS tablets		
Yes	40	77
No	12	23
I am unsure	0	0

Table 2: All the respondents, 52(100%), mentioned that they took their medication. The majority of the respondents, 38(73%), were stigmatized many times when taking HIV/AIDS medications, while the minority, 14(27%), were sometimes stigmatized. The majority of the respondents, 40(77%), found it hard to swallow their HIV/AIDS tablets, while the minority, 12(23%), said it was not hard.

Figure 1 shows the frequency at which respondents return to the hospital to pick up more medication. n=52

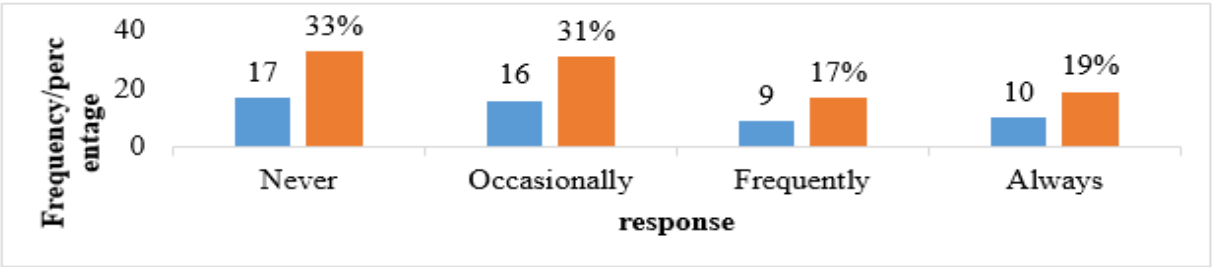

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Figure 1 shows that the majority of the respondents, 17(33%), never returned to the hospital to pick up more medication, 16(31%) occasionally returned to pick up more medication, 10(19%) always returned, while a minority, 9(17%), frequently returned to pick up medication.

Hospital-Related Factors Affecting Adherence to HIV/AIDS Treatment among Adolescents Attending Mildmay Hospital, Uganda, Wakiso District

Table 2 shows the hospital-related factors

Category	Variable	Frequency(n=52)	Percentage (%)
How health workers treat respondents when they visit the hospital	Very well Fairly well Very unfairly	7 18 27	13 35 52
Distance of the respondent from the nearest health facility that provides HIV/AIDS treatment	Less than 5 km 5-10 km More than 10 km	10 12 30	19 23 58
Frequency of missing HIV/AIDS treatment due to shortages or stockouts	Often Sometimes Never	22 19 11	42 37 21
Waiting time before receiving attention from health workers	Less than 10 minutes 10-15 minutes 15-20 minutes More than 20 minutes	3 5 8 36	6 10 15 69

Table 3 shows that more than half of the respondents, 27 (52%), were mistreated by the health workers when they went to collect their medication, 18 (35%) were fairly treated, while a minority, 7 (13%), were treated very well. The majority of respondents, 30(58%), lived more than 10 km from the nearest health facility that provides HIV/AIDS treatment, 12(23%) mentioned 5-10 km, while a minority, 10(19%), mentioned less than 5 km. The majority of respondents, 22(42%), frequently missed HIV/AIDS treatment due to stockouts or shortages, 19(37%) sometimes missed medicines, while a minority, 11(21%), never missed medications. The majority of respondents, 36(69%), waited more than 20 minutes before being attended to by health workers, 8(15%) waited for 15-20 minutes, 5(10%) waited for 10-15 minutes, while a minority, 3(6%) waited for less than 10 minutes.

Drug-Related Factors Affecting Adherence to HIV/AIDS Treatment among Adolescents Attending Mildmay Hospital, Uganda, Wakiso District

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Original Article

Figure 1 shows whether respondents found difficulties in swallowing HIV/AIDS drugs N=52

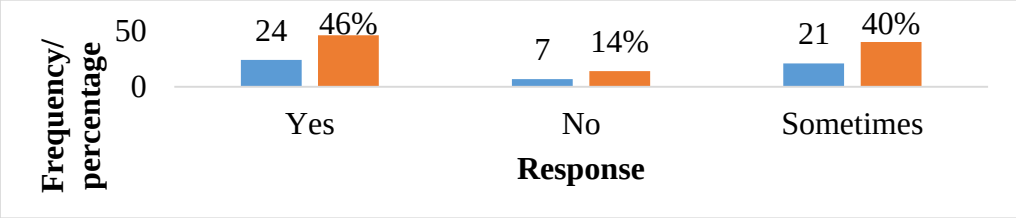

Figure 2 shows the majority of the respondents, 24(46%), found difficulties in swallowing HIV/AIDS drugs, 21(40%) sometimes found difficulties, while a minority, 7(14%), found no difficulties in swallowing their medication.

Table 3: shows others Drug-Related Factors Affecting Adherence to HIV/AIDS Treatment among adolescents

Variable	Frequency(n=52)	Percentage (%)
Having experienced any drug side effects that made them miss their doses.		
Yes	45	87
No	7	13
Not sure	0	0
The duration of HIV/AIDS treatment affected respondents' adherence to the prescribed regimen.		
Yes	41	79
No	11	21
Whether respondents struggled with adhering to their HIV/AIDS treatment		
Yes	5	10
No	47	90
Having doubts about the effectiveness of HIV/AIDS medication		
Yes	32	62
No	20	38

Table 4, the majority of the respondent, 16(43%), experienced drug side effects that made them miss their doses, while a minority, 7(13%), disagreed. The majority of respondents, 41(79%), said the duration of HIV/AIDS treatment significantly affected their adherence to the prescribed regimen, while a minority, 11(21%), mentioned to some extent that the duration of the treatment affected their adherence. Most of the respondents, 47(90%), struggled with adhering to their HIV/AIDS treatment when they changed their daily routines, while the least, 5(10%), disagreed. Most of the respondents, 32(62%), had doubts about the effectiveness of HIV/AIDS medication that caused them to miss doses, while the least 20(38%) disagreed.

Discussion

Individual Factors Affecting Adherence to HIV/AIDS Treatment among Adolescents Attending Mildmay Hospital, Uganda, Wakiso District

Regarding drug administration, all the respondents 52(100%) mentioned that they took their medication daily. This might have contributed to good outcomes in terms of viral load suppression. The findings of the study were contrary to the study done in India by Villiera et al. (2022), where findings showed that participants missed doses due to a lack of understanding of the importance of consistent treatment.

When taking medications, the majority of the respondents, 38(73%), were stigmatized many times when taking HIV/AIDS medications. This might have created an

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uncomfortable atmosphere that could have prevented respondents from taking their medication at the right time, eventually affecting their adherence. The findings of the study are similar to the study done by de Vos et al. (2023) in the Eastern Cape, South Africa, where findings showed that participants reported skipping doses due to peer pressure, and they feared being judged or ostracized by peers.

Furthermore, the majority of the respondents, 40(77%), found it hard to swallow their HIV/AIDS tablets. This could be because some medicines were a bit big, which might have made respondents miss doses at times. The findings of the study were in alignment with the study done by Niasse et al. (2020) in Ethiopia, which revealed that participants skipped doses due to food insecurity, as they avoided taking medication on an empty stomach, as it caused discomfort.

Pertaining to refills, the majority of the respondents, 17(33%), never returned to the hospital to pick up more medication. This could be because respondents never wanted to be seen at the facility, which might have contributed to failed adherence to the medication. The findings of the study are in alignment with the study done by Villiera et al. (2022) in India, where findings showed that participants struggled with adherence due to financial constraints, whereby those from low-income households were unable to afford transportation to health facilities, resulting in missed appointments and doses.

Hospital-Related Factors Affecting Adherence to HIV/AIDS Treatment among Adolescents Attending Mildmay Hospital, Uganda, Wakiso District

Concerning health workers, more than half of the respondents, 27(52%), were mistreated by the health workers when they went for their medication. This might have discouraged respondents from seeking medical attention and drug refills. The findings of the study are contrary to the study done by Norberg et al. (2019) in South Africa, where findings showed that adolescents who reported having positive and supportive relationships with healthcare providers adhered to their treatment.

Regarding distance, the majority of respondents, 30(58%), lived more than 10 km from the nearest health facility that provides HIV/AIDS treatment. The long distance to the facility might have discouraged respondents from seeking treatment. The findings of the study were in alignment with the study done in Zambia by Mesic et al. (2019), where findings showed that adolescents living more than 5 kilometers from healthcare facilities had poor adherence to their HIV/AIDS treatment compared to those living closer.

Furthermore, the majority of respondents, 22(42%), frequently missed HIV/AIDS treatment due to stockouts or shortages. This might have contributed to respondents' failure to follow their doses correctly, especially those who couldn't get the medications from elsewhere. The findings of the study are similar to the study from Kenya by Garollo Piran et al. (2023), where findings revealed that adolescents experienced treatment interruptions due to frequent stock-outs of HIV/AIDS medications during the COVID-19 pandemic.

Pertaining to waiting time, the majority of respondents, 36(69%), waited more than 20 minutes before being attended to by health workers. Long waiting times might have discouraged respondents from seeking treatment, since respondents were often engaged in school. The findings of the study are in agreement with the study done by Edwards et al. (2021) in Zambia, where findings revealed that adolescents missed appointments due to long waiting times attributed to staff shortages.

Drug-Related Factors Affecting Adherence to HIV/AIDS Treatment among Adolescents Attending Mildmay Hospital, Uganda, Wakiso District

Regarding swallowing, the majority of the respondents, 24(46%), found difficulties in swallowing HIV/AIDS drugs, and 21(40%) sometimes found difficulties. This might have discouraged respondents from accurately taking medicines following the routines, which might have contributed to failed adherence. The findings of the study were in agreement with the study done in Tanzania by Mesic et al. (2019), where findings showed that patients faced challenges with complex medication regimens.

About side effects, the majority of the respondent 16, 43%) experienced drug side effects that made them miss their doses. This might have contributed to respondents' poor adherence, especially when they completely got off the treatment, leading to complications. The findings of the study are similar to the study done in Uganda by Twekambe et al. (2023), where findings showed that adolescents cited side effects such as nausea and dizziness as a significant factor for non-adherence.

Concerning duration, the majority of respondents, 41(79%), said the duration of HIV/AIDS treatment significantly affected their adherence to the prescribed regimen. This could be because respondents felt a big burden of continuing

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medication, which forced them to opt to end their lives due to depression. The findings of the study were in agreement with the study done by Sabin et al. (2020), where findings revealed that adolescents reported difficulties maintaining consistent adherence due to the long duration of HIV/AIDS treatment.

Most of the respondents, 32(62%), had doubts about the effectiveness of HIV/AIDS medication that caused them to miss doses. This might have led to respondents quitting medication, having perceived that it was not working. The findings of the study agree with the study done in Nigeria by Richter (2023), where findings revealed that adolescents were influenced by cultural beliefs and misinformation, where they doubted the effectiveness of HIV treatment, favoring traditional remedies, which led to treatment discontinuation.

Conclusion

Regarding the individual factors, the study found that many adolescents reported experiencing stigma when taking medication. Difficulties in swallowing tablets and side effects such as nausea and dizziness were common, leading to missed doses. Additionally, some adolescents doubted the effectiveness of the medication or avoided returning for refills.

Hospital-related factors also played a role, whereby some adolescents were treated unfairly by health workers. Long distances to the health facility and frequent medication stockouts disrupted consistent access to drugs. Long waiting times were also reported.

Concerning drug-related factors, adolescents faced difficulties with swallowing large pills and managing side effects. The prolonged duration of treatment caused fatigue and emotional distress. Misconceptions and doubts about the effectiveness of the medication further contributed to poor adherence among the adolescents.

Limitations of the study

The cross-sectional design of the study did not allow for assessment of changes in adherence over time.

Adolescents who were lost to follow-up or severely ill were not included, potentially skewing the results.

The study did not explore the role of caregivers or family support in influencing adherence.

There was a limited assessment of psychological factors, such as depression or anxiety, that could affect treatment adherence.

The influence of school schedules and academic pressure on adherence was not thoroughly examined.

Recommendations

To Health Workers: Provide adolescent-friendly services that ensure respectful and supportive communication. Educate adolescents on the importance of adherence and how to manage side effects. Minimize waiting time through efficient appointment scheduling and staff allocation.

To Health Facility Management: Ensure consistent availability of HIV/AIDS medications to avoid stockouts. Train staff on handling adolescents with empathy and confidentiality. Establish follow-up systems to track missed appointments and support adherence.

To the Ministry of Health: Increase support for adolescent HIV programs, including counseling and education. Improve infrastructure and access to care by expanding treatment centers closer to communities. Provide funding for continuous drug supply and staff training on adolescent health needs.

To Parents and Guardians: Offer emotional support and encouragement to adolescents living with HIV. Monitor and assist with treatment adherence without being intrusive. Promote open communication to help adolescents express their challenges.

To Adolescents Living with HIV: Seek help from health workers or support groups when experiencing difficulties. Adhere to treatment schedules even when faced with stigma or side effects. Stay informed about the benefits of HIV treatment and avoid misinformation.

ACKNOWLEDGEMENT

I thank God wholeheartedly for His grace and enabling me to accomplish this research and the course. My sincere appreciation goes to my supervisor, Mr. Mpamize Habert, for the time he has given to my research, through his technical support, guidance, and direction during the development of this research work. I also thank the management of Mildmay Uganda School of Nursing and Midwifery, tutors and non-teaching staff, and also appreciate the management of Mildmay Hospital Uganda, Wakiso District, for accepting me to conduct my research from there.

May God richly bless them all.

LIST OF ACRONYMS

AIDS: Acquired Immunodeficiency Syndrome
ART: Antiretroviral Therapy

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COVID-19: Coronavirus Disease 2019
HIV: Human Immunodeficiency Virus
PMTCT: Prevention of Mother-to-Child Transmission
UHPAB: Uganda Health Professions Assessment Board

Source of funding
The study was not funded

Conflict of interest
The author did not declare any conflict of interest

Data availability
Data is available upon request

Author contribution
Elly Tabaaro collected data and drafted the manuscript of the study
Habert Mpamize supervised the study
Hasifa Nansereko supervised the study
Jane Frank Nalubega supervised the study
Immaculate Naggulu Prosperia supervised the study

Author biography
Elly Tabaaro is a student of a diploma in nursing at Mildmay Institute of Health Sciences.
Habert Mpamize is a tutor at Mildmay Institute of Health Sciences.
Jane Frank Nalubega is a tutor at Mildmay Institute of Health Sciences.
Hasifa Nansereko is a tutor at Mildmay Institute of Health Sciences.
Immaculate Naggulu Prosperia is a principal of Mildmay Institute of Health Sciences.

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Student's Journal of Health Research Africa
e-ISSN: 2709-9997, p-ISSN: 3006-1059
Vol.6 No. 9 (2025): September 2025 Issue
https://doi.org/10.51168/sjhrafrica.v6i9.2009
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Student's Journal of Health Research Africa
e-ISSN: 2709-9997, p-ISSN: 3006-1059
Vol.6 No. 9 (2025): September 2025 Issue
https://doi.org/10.51168/sjhrafrica.v6i9.2009
Original Article

PUBLISHER DETAILS.

Student's Journal of Health Research (SJHR)
(ISSN 2709-9997) Online
(ISSN 3006-1059) Print
Category: Non-Governmental & Non-profit Organization
Email: studentsjournal2020@gmail.com
WhatsApp: +256 775 434 261
Location: Scholar's Summit Nakigalala, P. O. Box 701432, Entebbe Uganda, East Africa