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Lived experiences of individuals with diabetes mellitus and HIV comorbidity in Kyamulibwa Sub-County, Kalungu District. A cross-sectional study.

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ABSTRACT

Background:

The study aimed to explore the lived experiences of individuals with diabetes mellitus and HIV comorbidity in Kyamulibwa Sub-County, Kalungu District.

Methodology:

This study employed a narrative inquiry qualitative design to explore the lived experiences of individuals with both diabetes and HIV in Kyamulibwa Sub-County, Kalungu district. Participants were purposively selected from patients previously involved in a 2022 Medical Research Council study, with a sample size of 10–15 determined by data saturation. Data were collected through in-depth interviews using a semi-structured guide, audio-recorded, and conducted in participants' homes. Thematic content analysis was applied using NVivo. Ethical approval and informed consent were obtained, ensuring confidentiality, credibility, and rigorous data management throughout the study.

Results:

Thematic analysis revealed seven core themes that characterized the lived experiences of participants. These included adherence to treatment, where managing multiple medications and complex regimens proved challenging; health care accessibility and quality; psychosocial adaptation, as individuals adapted their lifestyles and identities in response to dual diagnoses; and emotional and psychological resilience, built through personal strength, spirituality, and support networks. Other key themes were social support and community engagement, where family, peer groups, and community organizations played a critical role; treatment and medication management; and health literacy and patient empowerment, which varied among participants and influenced their ability to manage both conditions effectively. Two additional themes emerged as major barriers to accessing care: health care access and systemic challenges, including drug stock-outs, limited integration of services, and financial constraints; and cultural and personal beliefs, which shaped illness perceptions and influenced treatment decisions.

Conclusion:

People with HIV and diabetes showed resilience but faced stigma, financial challenges, and fragmented healthcare, limiting effective management.

Recommendation:

The Ministry of Health and healthcare providers should strengthen integrated, patient-centred care with improved education and reliable medication supply.

Keywords: *Human Immunodeficiency Virus, Diabetes Mellitus, Comorbidity, Lived Experiences, Treatment Adherence, Healthcare Access, People living with HIV.*
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BACKGROUND OF THE STUDY

Highly Active Antiretroviral Therapy (HAART) has significantly improved the survival of people living with HIV (PLWHIV) by reducing HIV-related morbidity and mortality (Getahun et al., 2020). However, with increased life expectancy, non-communicable diseases such as

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diabetes have emerged as major public health concerns among this population (Getahun et al., 2020). Evidence indicates that PLWHIV are at an increased risk of developing diabetes due to the effects of antiretroviral therapy and chronic inflammation, compounded by lifestyle and socioeconomic factors (Badacho & Mahomed, 2024; Godongwana et al., 2021). In resource-limited settings, managing both conditions is particularly challenging due to high treatment costs, limited access to care, and persistent HIV-related stigma (Sudipa & Brown, 2021).

Globally, there is increasing emphasis on integrating HIV and non-communicable disease care to improve patient outcomes (Adeyemi et al., 2021). Despite this, healthcare systems often remain fragmented, and even where integration exists, challenges persist, including poor service coordination and low patient awareness (Gilmara et al., 2019). In sub-Saharan Africa, diabetes prevalence among PLWHIV is estimated at 5%, with prediabetes affecting approximately 15%, and many cases remain undiagnosed despite regular healthcare contact (Peer et al., 2023). In South Africa, the dual burden is substantial, with about 8.2 million people living with HIV and 4.2 million with diabetes, projected to increase significantly (Makhabane et al., 2024). In Uganda, HIV prevalence stands at approximately 5.5%, while diabetes affects about 1.4% of the population, with studies reporting diabetes prevalence among PLWHIV ranging from 2.5% to 4.7% and notable levels of prediabetes (Ninsiima et al., 2024; Byereta et al., 2024).

The lived experiences of individuals with both HIV and diabetes are complex and multifaceted, involving physical, psychological, and social challenges. Managing dual conditions requires strict adherence to medications and lifestyle modifications, which can be difficult in low-resource settings (Shayo et al., 2023). Patients often experience stigma, discrimination, and social isolation, which negatively affect healthcare-seeking behavior and adherence (Nyongesa et al., 2022; Yang et al., 2021). Additionally, the burden of disease management contributes to mental health issues such as anxiety and depression (Rai et al., 2020). Fragmented healthcare systems further complicate care, as patients must navigate separate clinics for HIV and diabetes services, leading to increased financial and logistical burdens (Bukenya et al., 2022).

Although the World Health Organization recommends integrated, patient-centered approaches to managing HIV and comorbid conditions (Rugakingira et al., 2024), healthcare services in Uganda remain largely separated and under-resourced, particularly for diabetes care (Bukenya et al., 2022).

The study aimed to explore the lived experiences of individuals with diabetes mellitus and HIV comorbidity in Kyamulibwa Sub-County, Kalungu District.

METHODOLOGY

Study Design and Rationale

This study adopted a narrative inquiry qualitative design to gather information on the lived experiences of people living with both diabetes and HIV in Kyamulibwa Sub-County, Kalungu district. This design was used in order to give the researcher the ability to easily gather detailed information. It was effective in collecting data from a small number of sources to produce a valid and reliable generalization. Narrative inquiry, qualitative design, is well-suited for capturing personal stories and meanings that individuals attach to their health journeys. (Costantino, 2001).

Study Setting and Rationale

The study was carried out in Kyamulibwa Sub-County, Kalungu district, in central Uganda. The Medical Research Council in Kyamulibwa Sub-County serves a number of people from different cultural backgrounds within the rural areas of Kalungu district. Farming is their major economic activity. The study area was chosen because no studies have been conducted before in this area about the lived experiences of people living with both HIV and diabetes in the rural setting, thus the interest in the study in this area.

Study Population

All patients with a dual diagnosis of diabetes mellitus and HIV who participated in a study by the Medical Research Council in 2022 in Kyamulibwa Sub-County, Kalungu district.

Sample Size

The study aimed to collect data among 10-15 participants, but this was determined by the principle of saturation. Saturation is defined as sampling to the point at which no information is obtained, and redundancy is achieved. It is noted that a sample size of 6-18 is adequate for qualitative studies until saturation is reached around the number (6-12)(Moura et al., 2021).

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Sampling Procedure

The study used a purposive sampling procedure. Purposive sampling, also known as judgmental, selective, or subjective sampling, is a non- probability sampling technique where researchers deliberately select participants who possess certain characteristics or have specific experiences relevant to the research question. Purposive sampling allows researchers to focus on particular groups or individuals who can provide rich and in-depth information related to the research objectives (Ames, Glenton, and Lewin, 2019). Purposive sampling was used because it allowed the researcher to gather in-depth data on specific topics or issues. This provided valuable insights and understanding of the research question.

Inclusion criteria

Patients with a diagnosis of both diabetes and HIV, 18 years and above, who were able to talk and consent to participate in the study were included in the study.

Exclusion criteria

Participants who were not able to provide consent, the severely ill, had expressive or receptive aphasia, or had hearing disabilities.

Data collection tools

Data was collected using an interview guide comprising open-ended questions that enabled the researcher to obtain relevant information on lived experiences among people living with diabetes and HIV, with the interview guide interpreted from English to the local language (Luganda). An audio recording device was used to record the proceedings of the interview.

Data collection procedure

A letter was obtained from Mbarara University of Science and Technology giving the researcher permission to seek clearance from the authorities of Kalungu district to conduct her research study. This letter was taken to the office of the district health officer, Kalungu, who gave permission to the researcher to conduct her research in Kyamulibwa Sub-County. Both copies of the letters were presented to the head of the General Population Cohort of Medical Research Council in Kyamulibwa, who granted the researcher permission to use part of their data and also to carry out her research in the same population of interest. The researcher purposively sampled out her participants, introduced herself to them, and explained the reason as to why she wanted to carry out that research on an individual basis in their homes at the time of their convenience and with maximum privacy. The study used individual in-depth interviews for each respondent using a translated and non-translated interview guide that elicited a verbal response from the study participants, and an audio recorder was used to record the proceedings of the interview. The interview was conducted in private for each individual respondent, in a safe place within the respondent's home that ensured the comfort of the respondent and the confidentiality of their views.

Study variables

Dependent variable

In this study, the dependent variable was the Lived experience of patients, such as health management and self-care, psychosocial impact, access to healthcare, community support, social networks, and cultural influence.

Independent variable

In this study, the independent variables were diabetes and HIV, and demographic variables.

Rigors of research

Credibility

This is how confident the researcher is in the truth of the research study findings. (Ahmed, 2024). The researcher ensured credibility by probing the participants so as to obtain detailed information, reviewed the individual transcripts looking for similarities within and across all participants, maintained records of the interviews, and documented the process in detail.

Transferability

This is how the researcher demonstrates that the study findings are applicable to other contexts. (Ahmed, 2024). Other contexts can mean similar situations, similar populations, and similar phenomena in this case. The researcher therefore ensured transferability by providing in-depth details of the study setting, participants, and process that were observed during the interview to inform transparency and replication by another researcher if there was a need. A qualitative interview guide was carefully constructed, and additional probes were employed to achieve sufficient details of the phenomena.

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Dependability

This is the extent to which the study could be repeated, and consistent findings could be obtained by another researcher. (Ahmed, 2024). The researcher ensured that dependability was maintained by providing a detailed description of the research methods.

Data management

This ensured the integrity, security, and accessibility of data throughout the research process, and this involved a proper data management plan through proper data collection, storage, and handling at each stage of the research process. All data was anonymized, transcribed accurately, and organized systematically. Detailed records about each data file are maintained, institutional and legal guidelines for data protection and privacy are followed, and all files with data are securely stored.

Data analysis

The analysis commenced concurrently with data collection to allow the identification of key topics for further exploration during the ongoing study. To enhance familiarity with the data, an intensive reading of the transcripts was conducted to identify the emerging patterns within the data, which informed the development of a codebook. Codes were developed both deductively (based on the literature and study objective) and inductively based on what emerged from the interviews. The codebook was exported to NVIVO and applied to the transcripts until coding saturation was achieved, after which no new codes emerged. Thematic content analysis was used to analyze the data. Responses were categorized into themes, and then ideas were formulated by looking at the patterns of responses.

Ethical consideration

In undertaking this research, various sources were consulted in order to ensure that the study adhered to acceptable ethical guidelines. Before conducting data collection, ethical approval was provided to the researcher. The research proposal was submitted to the ethics committees of Mbarara University of Science and Technology as well as to the research committee of Kyamulibwa, Kalungu district, which was the intended study area for this study. This allowed the researcher to conduct the study within a limited time. To remain ethical, data collection was done only when all the required ethical clearances were obtained.

RESULTS

DEMOGRAPHIC DATA OF RESPONDENTS

Table 1 : The demographic characteristics of participants who participated in the study

The study involved Eleven (11) participants diagnosed with HIV and Diabetes in Kyamulibwa Sub-County, Kalungu district.

ID	Age	Sex	Tribe	Occupation	Living With	HIV Diagnosis	DM Diagnosis	Other NCDs
1	48	F	Muganda	Shop attendant	Child	20 years	1 year	None
2	64	F	Muganda	Farmer	Children and grandchildren	22 years	2 years	None
3	57	M	Muganda	Farmer	Children and wife	10 years	2 years	None
4	43	F	Muganda	Farmer	Daughter and grandchildren	3 years	8 years	None
5	68	M	Muganda	Farmer	Wife, Children, and grandchildren	20 years	4 years	None
6	54	M	Muganda	Farmer	Grand children	20 years	3 years	None
7	70	M	Muganda	Farmer	wife, children, and grandchildren.	15 years	3 years	HTN
8	59	F	Muganda	Farmer	An extended family with grandchildren.	10 years	2 years	None
9	60	F	Muganda	Business woman	Son	4 years	3 years	None

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10	60	F	Muganda	Farmer	Grand children	20 years	8 months	None
11	65	M	Muganda	Farmer	Wife and grandchildren	8 to 10 years.	1 year	None

Qualitative results

Nine (9) themes emerged from the study findings as lived experiences of people with diabetes and HIV in Kyamulibwa Sub-County, Kalungu District.

What are the lived experiences of people with diabetes and HIV in Kyamulibwa Sub-County, Kalungu District?

Table 2: Themes and sub-themes that emerged from the lived experiences of participants.

Sub themes	Theme
Adherence, Routine Adherence, Self-Management	Adherence to Treatment
Patient-Provider Relationship, Trust in Healthcare System, Health System Satisfaction, Health System Reliability	Health care accessibility and quality
Lifestyle Change, Coping Mechanisms, Life Adjustment	Psychosocial adaptation
Emotional Response, Emotional Strength, Resilience, Mental Health	Emotional and Psychological Resilience
Family Support, Disclosure, Community Leadership	Social Support and Community Engagement
Treatment Progression, Treatment Change, Tolerability, Herbal Alternatives	Treatment and Medication Management
Diagnosis Awareness, Multi-morbidity Awareness, Illness Understanding, Advocacy	Health literacy and patient empowerment
Financial Stress, Medication Supply Anxiety, Communication Barrier, Healthcare Navigation	Healthcare Access and Challenges
Illness Acceptance, Trust in Medical Advice, Sexual Health, and Herbal Preferences	Cultural and Personal Beliefs

Lived experiences of people with diabetes and hiv in Kyamulibwa Sub-County, Kalungu District.

Theme 1: Adherence to treatment

This theme emerged from three sub-themes, which included medication adherence, routine adherence, and self-management.

Participants consistently emphasized the importance of adherence to treatment for both HIV and diabetes as a vital part of managing their health. They described diligently following prescribed medication schedules, maintaining daily routines, and adopting self-management practices to control both conditions. Adherence was seen not only as a medical obligation but also as a personal responsibility for sustaining health and preventing complications. The participants' commitment to routine and medication highlighted a deep understanding of their conditions and reflected the crucial role that self-discipline and structured habits play in living with HIV and Diabetes in Kyamulibwa Sub-County, Kalungu District.

Sub-theme 1.1 Medication adherence

Participants reported following their prescribed regimen to the extent that some would rather cancel their travel appointments in order to not to miss out on taking their prescribed medication.

This is depicted from the responses below;

> *"...I cannot leave my medication, I would rather not travel, and take my medication…" (Interview 1)*
>
> *"...I get medicine and follow the way I am supposed to swallow it; I take it on time…" (Interview 8)*

Sub-theme 1.2: Routine adherence

The study also revealed that participants with both diabetes and HIV followed their routine for medication taking, thus supporting the fact that they adhere to their medication. Participants reported following the prescribed regimen.

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"...The good thing is I know the date, so when it arrives, I just go and pick up my medication and come back home..." (Interview 3)

"…I take my medication at 7 am, and I do my work..." (Interview 10)

Medication adherence routine was also mentioned among participants who often mentioned taking medication with them to every place they go. This came from responses such as;

"...I move with my medication so it became like my ID…" (Interview 5)

Sub-theme 1.3: Self-management

Participants developed confidence in self-administering insulin, as shown in acceptance of Self-Injecting. This was noted from responses such as;

"…As long as you hold this flesh like this, and you inject it here, it's so good…" (Interview 7)

Participants shared to have adopted the use of tools and family help for monitoring health. These proved to be helpful when it comes to Self-management of Diabetes. This came from a response such as;

"…For diabetes, we even bought a machine, now my children always monitor..." (Interview 6)

Theme 2: health care accessibility and quality

This theme emerged from four sub-themes, which included patient-provider relationship, trust in health care, health system satisfaction, and health system reliability.

The healthcare accessibility and quality emerged as a key theme influencing health-seeking behavior and adherence to treatment among individuals living with diabetes and HIV. Participants reported positive experiences with healthcare workers, highlighting trust, empathy, and timely communication as fundamental to their continued engagement with care. Trust in the healthcare system, reliability of medication access, and satisfaction with service delivery reinforced patients' commitment to treatment routines. Consistent provider support not only shaped patients' confidence but also enhanced their overall health outcomes, revealing that strong provider relationships serve as a cornerstone for effective HIV and Diabetes management in Kyamulibwa Sub-County, Kalungu District.

Sub-theme 2.1: Patient-provider relationship

Participants described the patient-provider relationship as a significant influence on their ability to manage both HIV and diabetes. For many, the quality of communication, level of empathy, and provider's attentiveness shaped their engagement with treatment. This is depicted from the responses below;

"…I have found that the medical workers are kind people. Especially when explaining what we call counseling..." (Interview 6)

"…The medical staff are good; they handle us with care..." (Interview 4)

Sub-theme 2.2: Trust in the health care system.

Participants' trust in the health care system played a pivotal role in how they accessed, adhered to, and engaged with care for both HIV and diabetes. The level of trust was influenced by several factors, including the consistency of care, availability of medications, quality of communication, and overall treatment outcomes. This can be exhibited through the following responses;

"...I have found that the medical workers are kind people... counseling... stopped worrying..." (Interview 5)

"...If a health worker tells me something, I have to believe..." (Interview 2)

Sub-theme 2.3: Health system satisfaction.

Participants' satisfaction with the health system significantly influenced their motivation to engage with care and maintain treatment for both HIV and diabetes. This is exhibited in the following responses;

"…Starting the ART drugs wasn't easy... the medical staff gave me happiness…" (interview 8)

"…We appreciate the organization, and we are happy because it has helped us a lot with our colleagues…" (Interview 7)

"…The medical staff are good; they handle us with care…" (Interview 4)

Sub-theme 2.4: Health system reliability.

Participants frequently described the reliability of the health system as a critical factor in successfully managing both HIV and diabetes. Reliability in this context referred to the consistent availability of medications, timely access to services, follow-up care, and dependable information from health care providers. Reliability with the health care system fosters positive responses of the participants' adherence to treatment of chronic diseases such as HIV and diabetes in this case. Participants felt that the health system was generally reliable, as in the following responses;

"…There's no day I have gone there, and they say that the ARTS drugs are not there…" (Interview 8)

"...I have been getting my medication, I don't have any challenges..." (Interview 3)

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However, there was a wave of worry about the reliability of the health care system, if at all, the USA government would freeze its aid as per the response below;
"...I feel scared and shocked... if the USA stops its aid... the health sector had a low percentage..." (Interview 5)

Theme 3: psychosocial adaptation

This theme emerged from three sub-themes, which included: lifestyle change, coping mechanisms, and life adjustment.
Living with both HIV and diabetes requires individuals to undergo significant behavioral and emotional adjustments. This theme explores how participants adapted their daily lives through lifestyle changes, developed coping mechanisms, and made broader life adjustments to manage their dual diagnoses. Participants highlighted significant lifestyle changes following their diagnosis with HIV and diabetes. These adjustments included modifying daily routines, altering dietary habits, reducing sugar intake, and adopting healthier living practices to cope with both conditions. Many shared how they consciously avoided risk behaviors and embraced positive coping mechanisms to maintain their well-being. This life adjustment was often seen as a long-term commitment that required discipline, family support, and self-awareness. The willingness to adapt not only reflected their determination to manage their health but also revealed the emotional and social resilience needed to live with chronic conditions in Kyamulibwa Sub-County, Kalungu District.

Sub-theme 3.1: Lifestyle change

Participants reported adopting new routines to manage their health, including dietary changes, medication adherence, and physical activity, as per responses below;
"...We are supposed to eat greens/vegetables, you eat something sour, and eat fruits like ".... I didn't take table sugar and sweet things, sodas... Now I always go back for a checkup...." (Interview 5)
"...I didn't take table sugar and sweet things, sodas and others, I left them all, and I no longer use them..." (Interview 6)
Participants adopted work as therapy, *".... It helped me a lot, those days when I used not to dig, I could not walk up to the stage..." (Interview 4)*

Sub-theme 3.2: Coping mechanisms

Participants employed a variety of coping strategies to deal with the emotional and physical burden of managing two chronic diseases. These included religious faith, social support from peers and family, and maintaining a positive outlook.
"...As I dress up, my wife reminds me of even my home helper, they say 'muzee endagala lyo..." (Interview 6)
"...I decided to trust God, and I said nothing comes when God doesn't know of it."... (Interview 1)

Sub-theme 3.3: Life adjustment.

Beyond medical routines, participants spoke out about deeper adjustments in their social life, work, and personal identity in order to prioritize health as per responses below;
"...It helped me a lot, those days when I used not to dig, I could not walk up to the stage..." (Interview 4)
..."At the start, I used to fear, but now, I see it as a usual thing."... (Interview 3)

Theme 4: emotional and psychological resilience

This theme emerged from four sub-themes, which included emotional response, emotional strength, resilience, and mental health.
Managing both HIV and diabetes was described by participants not only as a physical struggle but also as a significant emotional and psychological journey. Participants described a wide range of emotional and psychological responses upon learning of their HIV and diabetes diagnoses. Initial feelings of shock, fear, and uncertainty were commonly shared, yet many individuals revealed how they gradually built emotional strength and resilience over time. Acceptance of their health conditions often required mental adjustment, as well as emotional support from family, friends, and healthcare providers. Despite the emotional toll, participants demonstrated remarkable determination to manage stress, maintain a positive outlook, and prioritize mental health as a vital part of coping with the realities of living with chronic illness.

Sub-theme 4.1: Emotional response

Most participants described intense emotional reactions upon receiving the diagnosis, and the common emotions included shock, fear, sadness, and, at times, anger or denial. This is depicted from the responses below;
"...I was worried, got so scared, and asked myself where I got the disease..." (Interview 9)

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"…You get overwhelmed. You get stressed, and at times, you lose hope when you see that the conditions are not improving..." (Interview 4)
"...I have a very bad effect, even got mental issues..." (Interview 8)

Sub-theme 4.2: Emotional strength

Over time, participants developed emotional strength that allowed them to better manage the challenges of living with two chronic illnesses. This strength often came from within but was also supported by family, faith, and peer groups.
"... I love life, and I have seen most people... they died... but I am still alive…" (Interview 5) "I view it as a game, that is to say, I have to take my medication daily even if I am sleeping..." (Interview 2)
"...My heart became strong, and I accepted that all other people are like me."
"I decided to trust God, and I said nothing comes when God doesn't know of it…."(Interview 1)

Sub-theme 4.3: Resilience

Participants demonstrated resilience in various ways: persisting with treatment despite financial hardship, stigma, or side effects; adapting to new lifestyles and continuing to pursue their personal goals.
"...Back then, medicine was expensive... sometimes I used to swallow sparingly so it could last me for a longer period…"(Interview 2)
"...The tablets we are given are not easy to swallow, but you have to swallow nothing to do…" (Interview 3)

Sub-theme 4.4: Mental Health

The early phases of diagnosis are not easy for every individual, thus demonstrating a mental impact on the participants' health as per the following responses;
"...I was worried, got so scared, and asked myself where I got the disease…." (Interview 9)
"...I have a very bad effect, even got mental issues..." (Interview 8)
"…You get overwhelmed. You get stressed, and at times, you lose hope when you see that the conditions are not improving..." (Interview 4)

Theme 5: social support and community engagement

This theme emerged from three sub-themes, which included: family support, disclosure, and community engagement.

Participants highlighted the critical role of family and social networks in managing their lives with HIV and diabetes. Disclosure of their health status to family members, particularly spouses, was described as an essential step toward receiving emotional and practical support. Family members often encouraged treatment adherence and accompanied them to healthcare facilities. Additionally, the sense of belonging within community circles and leadership roles empowered some individuals to share their experiences and offer guidance to others facing similar conditions. Social support systems emerged as both a source of strength and a foundation for resilience in their daily health journeys.

Sub-theme 5.1: Family support

Many participants described family as a vital source of strength. Family members offered emotional reassurance, financial assistance for medication or transport, and even reminders to take or attend appointments. This is depicted in the responses below;
"...Keeping time which was given to us, secondly, having a partner to remind you..." (Interview 5)
"...As I dress up, my wife reminds me of even my home helper, they say 'muzee edagala lyo…'" (Interview 6)

Sub-theme 5.2: Disclosure

The decision to disclose one's HIV or diabetes status was deeply personal and often influenced by fear of stigma or hope for support. Some participants disclosed openly and received positive responses:
"….My wife knows; she even knows where I keep my medication…." (Interview 3)
"…….The most important thing that brings problems is people... deciding to hide it away from those at home……" (Interview 7)
"...They know very well that it's not good to hide illness; it's always good to let your people know…"(Interview 8)
Others were selective in disclosure, revealing their health status only to those they trusted
"….. I even stay alone; I stay with only my little boy... For visitors... I don't allow them to know……." (Interview 1)
"...We are twins; my sister in Masaka knows... my grandchildren know, since they see me take medicine…" (Interview 10)

Sub-theme 5.3: Community leadership

Participants noted that Community leaders and local figures have a strong influence in shaping community attitudes toward HIV and diabetes, thus some chose to be part of the

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local figures to fight stigma. This is depicted from the following responses;
"...I am in the church, I have been the treasurer for 35 years now, there's a school, and it's now 40 years still as chairman..." (Interview 7)

THEME 6: Treatment and medication management

This theme emerged from four sub-themes as noted: treatment progression, treatment change, tolerability, and herbal alternatives.

Participants' lived experiences with HIV and diabetes treatment reflected a dynamic journey of adaptation and self-awareness. Many shared stories of starting on conventional medication and adjusting over time based on effectiveness and tolerability. Some transitioned to herbal alternatives, especially for diabetes, citing personal comfort and cultural familiarity. Treatment progression was not only shaped by clinical guidance but also by the individual's response to medication and willingness to manage side effects. This theme highlights the participants' continuous evaluation of their treatment paths, reflecting both confidence in medical advice and flexibility in using alternative remedies to maintain well-being.

Sub-theme 6.1: Treatment progression

Most participants described their treatment journey as a gradual progress of learning and adjustment. Over time, they became more knowledgeable about their medications and better at integrating them into daily routines;

"…Back then, medicine was expensive... sometimes I used to swallow sparingly so it could take me for a longer period…"(Interview 2)
"…It wasn't easy, I could have nausea, and I had dreams in the night. But it went on stopping..."(Interview 3)

Sub-theme 6.2: Treatment change

There were reports about drug changes by participants, and this was due to either side effects, drug resistance, or evolving health needs. This is depicted from the following responses;

"…We used to take two tablets, but still once a day... now we take one…"(Interview 3)
"…They changed it from three to two tablets, I also take septrin…" (Interview 9)

Sub-theme 6.3: Tolerability

Tolerating daily medication for two chronic conditions was a major concern for participants, and despite these challenges, most participants chose to continue treatment, citing the long-term benefits.

"…It wasn't easy, I could have nausea, and I had dreams in the night. But it went on stopping..."(Interview 3)
"…. Now, for me, those drugs no longer give me a hard time... it turned into something good..." (Interview 6)

Sub-theme 6.4: Herbal alternatives

Some participants reported using herbal remedies or traditional medicine either alongside or in place of biomedical treatment.

"……The Baganda call it 'ngalo tano', it's where we passed…." (Interview 2)

THEME 7: Health literacy and patient empowerment

This theme emerged from four sub-themes, which included: diagnosis awareness, multi-morbidity awareness, illness understanding, and advocacy.

Participants described their health awareness as a transformative experience that shaped their journey with HIV and diabetes. Receiving a clear diagnosis gave them a sense of direction and control, reducing fear and uncertainty. Their growing understanding of living with multiple chronic illnesses encouraged both self-care and proactive decision-making about their health. Additionally, this awareness often extended beyond the individual, as participants shared their knowledge within families and communities, becoming informal advocates for early testing and treatment. This experience fostered confidence, reduced stigma, and promoted healthier lifestyles within their social circles.

Sub-theme 7.1: Diagnosis awareness

Participants described the moment they were first diagnosed as a turning point; they often met with shock, confusion, and denial. This is depicted from the following responses;

"...I got HIV in 1978 and stayed with it, then tested after a while..." (Interview 7)
"...My heart became strong, and I accepted that all other people are like me."
"I decided to trust God, and I said nothing comes when God doesn't know of it…"(Interview 1)
"…Starting the ART drugs wasn't easy... the medical staff gave me happiness…" (Interview 8)

Sub-theme 7.2: Multi-morbidity awareness

With time, many participants came to understand the interactions between HIV and diabetes and how managing

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both required balance and discipline. This awareness developed gradually through personal experience or education during clinic visits.
"...I advise people to always seek medical checkups and know their status..." (Interview 5)
"… HIV, blood pressure, and diabetes are close. If there are neighbors, one is in the sitting room, and the other is in the bedroom…." (Interview 7)

Sub-theme 7.3: Illness understanding

Beyond knowing their diagnoses, participants developed varying levels of comprehensive illness understanding, including causes, medication effects, and long-term risks. This is evident in the following responses;
"...We are alive because of ART drugs, and that's how we are to live…." (Interview 6)
"...If you take medication in the right way, you find everything easy..." (Interview 7)
"...leave sugar, soda, and fried things... half of it should be vegetables…" (Interview 8)

Sub-theme 7.4: Advocacy

Some participants became advocates within their communities or families, using their experiences to educate and support others.
".... I advise people to always seek medical checkups and know their status…." (Interview 5)
"...I advise people to always seek medical checkups, and know their status, but if you are in this condition, just accept that's how you will live until God decides to turn around that condition…" (Interview 6)
"...I am in the church, I have been the treasurer for 35 years now, there's a school, and it's now 40 years still as chairman..." (Interview 7)

Theme 8: healthcare access and challenges

This theme emerged from four sub-themes, which included: financial stress, medication supply anxiety, communication barrier, and health care navigation.
Participants' experiences highlighted that navigating healthcare services for HIV and diabetes was shaped by both personal resilience and structural barriers. Many faced financial stress that limited their ability to consistently access medication and routine checkups. Uncertainty about medication supply created ongoing anxiety, especially for those reliant on public health facilities. Communication gaps between healthcare workers and patients, along with difficulty navigating referral systems, often leave individuals feeling isolated or uninformed about their care options. Despite these challenges, participants adapted and learned to overcome some barriers, revealing both their resourcefulness and the need for system-wide improvements.

Sub-theme 8.1: Financial stress

The cost of care was a significant concern for many participants. Even when medications were free, indirect costs such as transportation, specialized diets, diagnostic tests, and lost income weighed heavily;
"...Back then, medicine was expensive... sometimes I used to swallow sparingly so it could last me for a longer period..." (Interview 2)
"...I went to Virus in Kyamulibwa...transport was a challenge, but I used to get my medication in time because sometimes the drug wasn't there..." (Interview 2)
"….. It's a bit challenging to get money…." (Interview 9)
"...For diabetes, we even bought a machine, now my children always monitor…" (Interview 6)

Sub-theme 8.2: Medication supply anxiety

Participants expressed anxiety about the reliability of medication supply, particularly for diabetes drugs, insulin, or certain ARV combinations;
"...I feel scared and shocked... if the USA stops its aid... the health sector had a low percentage..." (Interview 6)
"……They take like 2 days, and they tell you that there's no medicine……" (Interview 9)
"...I went to Virus in Kyamulibwa...transport was a challenge, but I used to get my medication in time because sometimes the drug wasn't there..." (Interview 2)

Sub-theme 8.3: Communication barrier

Some participants faced a challenge in communication, which is expressed through their failure to talk to their healthcare providers;
"…I first feared." / "I just kept quiet because it disturbs me a lot…" (Interview 9)

Sub-theme 8.4: Health care navigation

Navigating between different departments, clinics, or service points was often tiring. Participants spoke of long wait times, referral delays, and lack of coordination as depicted in the responses below:
"...At MRC, you go there and spend the whole day... you feel like that situation is challenging..." (Interview 1)
"...I was at MRC, and MRC sent me to MUSANYA, but at MUSANYA I don't [get] treatment very well..." (Interview 9)

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"…The day for collecting diabetes medication is different from that of getting ART drugs…" (Interview 1)

THEME 9: Cultural and Personal Beliefs as Barriers in Illness Management

This theme emerged from four sub-themes, which were: illness acceptance, trust in medical advice, herbal preferences, and cultural and personal beliefs.

Participants described how cultural and personal beliefs sometimes posed challenges in the management of HIV and diabetes. Delayed illness acceptance often resulted in late treatment initiation or inconsistent medication use. Distrust in medical advice, shaped by prior experiences or community narratives, affected health-seeking behaviour. Sexual health choices were influenced by fear of stigma or misunderstanding about disease transmission, which affected open communication with partners and healthcare providers. Additionally, the preference for herbal remedies over prescribed medication sometimes interfered with adherence and treatment effectiveness, highlighting the complex role of cultural practices in health management.

Sub-theme 9.1: Illness acceptance

Many participants described a personal journey of coming to terms with their diagnoses, which often involved emotional turmoil, spiritual reflection, and eventual adaptation. This is depicted from the responses below;

"… At the start, I used to fear, but now, I see it as a usual thing..." (Interview 3)

"…Finding someone you are familiar with, in fear that they might backbite you..." (Interview 1)

"...I got it in 1978 and stayed with it then tested after a while, that's when I expected to have acquired it..." (Interview 7)

Sub-theme 9.2: Trust in medical advice

Participants expressed their levels of trust in medical advice. Some expressed deep faith in their health care providers and the prescribed treatments:

"…the medical staffs are good; they handle us with care…" (Interview 4)

"…If a health worker tells me something I have to believe..." (Interview 2)

"…You are told to come on an empty stomach... however long the line is, you have to follow its order..." (Interview 1)

Sub-theme 9.3: Herbal preferences

Some participants believed in the complementary benefits of herbs.

"…We are supposed to eat greens/vegetables, you eat something sour, and eat fruits like oranges, pawpaw…" (Interview 2)

"…The Baganda call it 'ngalo tano', it's where we passed..." (Interview 2)

Sub-theme 9.4: Cultural and personal beliefs

Participants' religious beliefs, cultural norms, and personal worldviews significantly shaped their coping strategies and treatment decisions. Some spiritual practices provided strength and healing; however, some cultural attitudes towards illness and stigma influenced how participants experienced their conditions.

"…We stay in the village; you might wake up in the morning when you didn't prepare what to eat early morning..." (Interview 2)

"...The medicine became too much for me, I had to take this, and that, and I also had to work..." (Interview 2)

"…People might talk, others may not tell you, but they know, and they talk in your absence..." (Interview 3)

DISCUSSION

Adherence to Treatment

Results show that participants emphasized the importance of strict adherence to prescribed medication for both HIV and diabetes. They demonstrated a high level of self-discipline in maintaining medication schedules, routine follow-up visits, and lifestyle adjustments. These findings mean that adherence to treatment was described as a survival strategy rather than a choice. For many, the awareness of the consequences of non-compliance shaped their commitment to the regimen, especially for HIV, where structured counselling is commonly available. This study finding is in agreement with evidence by (Powers et al., 2020) who reported that managing both diabetes and HIV requires substantial self-care efforts, including medication adherence, dietary adjustments, and regular health check-ups. In contrast, adherence to diabetes medication was more variable, as some patients even denied being diagnosed with Diabetes. Those who accepted did not have a clear management plan, and others presented challenges in managing the condition. This finding matches findings that individuals often face challenges in maintaining their routines due to the overlapping demands of both conditions (Ohueri et al., 2022). These findings can be explained by the fact that the established and often well-supported HIV programs in Uganda provide an enabling environment for adherence. On the other hand, diabetes management is left largely to self-monitoring due to limited community

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outreach or public education, leading to occasional lapses in adherence.

Healthcare accessibility and quality

The findings from this study revealed that healthcare accessibility and quality play a central role in the health-seeking behaviour and treatment adherence of individuals living with HIV and diabetes in Kyamulibwa Sub-County, Kalungu District. Participants repeatedly emphasized trust, kindness, empathy, and clear communication from healthcare providers as pivotal factors influencing their comfort, willingness to adhere to medication regimens, and satisfaction with health services. Respondents highlighted appreciation for professional advice over alternative remedies and recognized reliable medication availability and positive counselling experiences as enhancing their treatment journey. These results suggest that a respectful, communicative, and supportive healthcare environment significantly shapes patient engagement and health outcomes. Trust and human connection between patients and providers reduce emotional stress and health system scepticism, fostering adherence to both HIV and diabetes treatments. The repeated emphasis on professional advice and counselling indicates that emotional reassurance is as important as clinical care in chronic disease management. Findings are supported by a study by (Trepka et al., 2023) who documented that a strong patient–provider relationship facilitates ART adherence. This can be explained by the fact that in Kyamulibwa, where economic challenges and health literacy gaps persist, the healthcare provider often becomes the most consistent and trusted source of both medical and emotional support. This agrees with the study findings by (Bosire et al., 2021) who emphasized the crucial role of health care providers in supporting self-care through education, regular follow-ups, and encouragement of adherence to treatment plans. When patients perceive providers as empathetic and knowledgeable, they feel empowered and reassured in navigating the complexities of dual conditions like HIV and diabetes. Moreover, the reliability of medication supply, as reported, and consistent, respectful communication likely strengthen this relationship, reducing patient anxiety and improving adherence behaviours.

Psychosocial adaptation

Participants reported significant changes in their daily lives, including dietary adjustments, cessation or moderation of alcohol use, and incorporating exercise or stress management practices. These findings mean that participants viewed lifestyle change as both a coping mechanism and a form of self-preservation. These changes reflect the perceived seriousness of living with two chronic conditions. The findings of this study are in agreement with evidence by, who reported that People living with HIV stopped or reduced hazardous drinking primarily due to being motivated by their HIV condition and desire for longevity.

Emotional and Psychological Resilience

Participants reported experiencing a wide spectrum of emotions from initial fear and despair to later resilience and emotional strength in the face of their diagnoses. These findings mean that emotional adjustment appeared to be a process shaped by time, as evidenced by the demographic data of the participants. Most participants have been treated for HIV for 3 to 20 years. Through this, they have developed support systems and personal reflection. This experience of living with both conditions led to a form of "emotional hardening," where participants learned to cope and accept their health status. These findings are in line with (Tecson et al., 2019) who reported that Psychological resilience may be a resource to preserve well-being for chronically ill individuals. These findings contradict a conclusion made by (Tusubira et al., 2020; Abubakari et al., 2021). Despite the importance of emotional and psychological resilience, many individuals face barriers in accessing psychosocial support. This is due to the fact that stigma, lack of awareness, and limited availability of resources can hinder effective support. (Tusubira et al., 2020; Abubakari et al., 2021). The findings of this study can be explained by the fact that cultural and social norms in rural Uganda promote silence around emotional distress, which may push patients toward developing internal resilience or relying on family members for emotional support.

Social Support and Community Engagement

Participants highlighted the indispensable role of family, friends, and community leaders in their treatment journey. Disclosure, though often challenging, was usually met with supportive responses that facilitated adherence and emotional comfort. These findings mean that the involvement of social support systems was critical for both psychological health and adherence to treatment plans. Disclosure reduced feelings of isolation and encouraged health-seeking behaviour. This is in agreement with a study conducted in China that reported perceived social support as a partial mediator between family health and self-efficacy

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among patients with chronic conditions. Furthermore, (Ohueri et al., 2022) Their study supports the findings by complementing that support from family, friends, and community organizations plays a crucial role in coping with the challenges of living with diabetes and HIV. Peer support groups have been shown to improve self-management skills and reduce feelings of isolation. This finding can be explained by the fact that in rural Ugandan communities, the concept of extended family and collective living makes social support more accessible. Disclosure helps convert family members into informal caregivers, which eases the daily burden of disease management.

Treatment and medication Management

Participants reported varying experiences in treatment progression, including side effects, drug changes, and sometimes the integration of herbal remedies, especially for diabetes. These results mean that treatment progression for diabetes appeared less predictable than for HIV, with several participants self-modifying or supplementing medical treatment with herbal alternatives. This finding is supported by a study that reports the use of herbal medicines, but there is a lack of communication about it with the healthcare providers. The findings also agree with evidence by (Lema et al., 2024) that found that 48.1 % (95 % CI: 43.3–53) participants used herbal medicine, and concluded that Herbal medicine use was common among diabetes patients in this study. For HIV, the structure and reliability of antiretroviral treatment (ART) systems offered a more stable experience. This finding can be explained by the fact that the disparity in medication reliability and system support between HIV and diabetes management may prompt patients to fill treatment gaps using herbal remedies, especially when costs or stock-outs prevent full adherence to prescribed diabetes medication.

Health literacy and patient empowerment

Participants displayed more confidence in their understanding of HIV than in their understanding of diabetes. HIV knowledge was generally high, while diabetes awareness varied significantly between participants. This result means that public health campaigns have significantly improved HIV awareness, whereas diabetes lacks equivalent outreach, leaving many patients under-informed about the disease and its management. This finding is similar to a study by (Kagaruki et al., 2018) from Tanzania that reported a Considerable number of respondents having a low level of knowledge (41.1%) regarding Diabetes and other chronic conditions, such as hypertension. The findings are also supported by a study by (Alcantara et al., 2025) who reported a general lack of awareness of Diabetes among older adults with HIV. These findings can be explained by the fact that Government and donor funding heavily prioritize HIV, creating robust educational infrastructure for HIV patients, while diabetes education depends more on individual encounters with healthcare providers or community hearsay.

Healthcare Access and Challenges

Participants frequently cited financial stress, medication shortages (particularly for diabetes), and healthcare navigation difficulties as barriers to effective disease management. These results mean that despite the accessibility of HIV services through government programs, diabetes care was often inconsistent and expensive. Many participants expressed anxiety over medication stock-outs and unaffordable diagnostic tests. These findings are supported by evidence. (Walker et al., 2021) that reported that difficulty paying bills and cost-related medication non-adherence are associated with glycaemic control. This study aimed to document that every additional financial hardship was associated with an increased HbA1c of nearly 0.1%. (Bukenya et al., 2022) Further agrees with the study findings by documenting in their report that despite access to appropriate healthcare services being critical, it was often hindered by socioeconomic factors such as lack of insurance, and logistical issues such as transportation, discrimination, and systemic barriers. The study findings can be explained by the fact that Uganda's healthcare system, like many others in the region, remains disease-specific in its funding and organization. This creates inequitable access where some conditions receive comprehensive support, while others rely on out-of-pocket expenditures, increasing stress for patients managing both HIV and diabetes.

Cultural and Personal Beliefs as Barriers in Illness Management

The study identified that cultural and personal beliefs significantly influenced how participants managed their dual diagnosis of HIV and diabetes in Kyamulibwa Sub-County, Kalungu District. Delayed illness acceptance, distrust in medical advice, preference for herbal alternatives, and traditional attitudes toward sexual health were cited as challenges. These beliefs often interfered with timely treatment initiation, medication adherence, and health-seeking behaviour, while social stigma and misconceptions shaped patient relationships with healthcare providers and

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partners. These findings suggest that cultural and personal frameworks shape not only attitudes toward illness but also daily health management decisions. Delayed acceptance of a diagnosis, especially for diabetes, often resulted in procrastinated medication uptake or lifestyle adjustments. Trust gaps between medical advice and community-shared knowledge created hesitation and inconsistency in following prescribed treatment plans. Additionally, reliance on herbal remedies or home-based interventions sometimes compromised formal treatment, and fear of stigma limited open dialogue about sexual health and disease transmission, leading to partial or poor adherence. The findings of this study are supported by a number of studies on different grounds such as evidence on Stigma related to both conditions varies across cultures, influencing health behaviours and perceptions of illness (Akugizibwe et al., 2023), perceptions of the illness, engaging with treatment regimens, and interact with healthcare systems (de Wit et al., 2020), the interpretation and management of diabetes and HIV (Aidoo-Frimpong et al., 2021). This can be explained by the fact that participants' experiences reflect the tension between modern medical advice and long-standing cultural traditions. Limited access to early, clear, and repeated health education allows misinformation and stigma to persist, especially regarding chronic illness management. Additionally, the integration of herbal alternatives into daily routines is often born out of accessibility, affordability, and social trust in traditional medicine rather than outright rejection of biomedical treatments. The struggle to balance economic survival, food insecurity, and illness management, especially in rural settings like Kyamulibwa, compounds these beliefs, reinforcing delays and inconsistencies in treatment adherence.

This underscores the importance of culturally sensitive healthcare strategies, ongoing community health education, and collaborative patient-provider relationships to address the psychosocial and cultural dimensions of living with HIV and diabetes.

CONCLUSION

The study found that participants showed remarkable strength in adjusting their lifestyles, adhering to complex treatment regimens, and coping emotionally with both conditions. The experiences were shaped by strong patient-provider relationships, family support systems, and personal resilience. However, the journey was not without struggles, as emotional stress, social stigma, and cultural beliefs often complicated acceptance and self-management of the diseases.

The study highlighted several issues, including financial constraints, inconsistent medication supply, communication gaps between patients and providers, and the influence of cultural and herbal treatment preferences. These barriers not only affected adherence and treatment success but also limited patients' full trust in the health system and delayed timely care-seeking.

In conclusion, the lived experience of people with HIV and diabetes in Kyamulibwa is marked by both resilience and vulnerability. While strong social and healthcare relationships play a crucial role in sustaining health, gaps in healthcare delivery, cultural beliefs, and economic hardship remain significant barriers to effective management. These insights highlight the need for patient-centred health system strengthening, targeted community education, and culturally responsive healthcare policies.

RECOMMENDATION

While this study provides important insights into the lived experiences and healthcare barriers faced by individuals living with both HIV and diabetes in Kyamulibwa Sub-County, Kalungu District, several limitations are worth noting.

One key limitation was the uncertainty and denial of diagnosis reported by some participants regarding their diabetes status. A few individuals expressed scepticism or hesitation in fully accepting their diabetes diagnosis, which could have affected the accuracy and depth of their responses related to disease management, adherence, and lifestyle adjustment. This highlights the broader issue of underdiagnosis and limited health literacy, which could have influenced the study's findings.

Additionally, the study was limited by its small, non-random sample size, which restricts the generalizability of the results to other populations or geographic areas. Because this research relied on self-reported experiences, there is a risk of recall bias and social desirability bias influencing the authenticity of some narratives, particularly around sensitive topics like sexual health, medication adherence, and the use of herbal alternatives.

Another limitation is the lack of healthcare provider and family perspectives, which could have enriched the understanding of the systemic, cultural, and interpersonal dynamics involved in managing both HIV and diabetes.

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Healthcare providers should prioritize continuous patient education, especially around diabetes diagnosis, illness acceptance, and the dangers of mixing herbal remedies with prescribed medications.
Training programs that emphasize empathy, clear communication, and cultural sensitivity should be implemented to further strengthen trust between patients and healthcare providers.
Government and non-government actors should work to address logistical barriers such as medication shortages, financial strain, and transportation challenges that disrupt continuity of care.
Leveraging local leaders and peer support groups could help to reduce stigma, encourage disclosure, and promote adherence to treatment for both conditions.

List of abbreviations

HIV – Human Immunodeficiency Virus
AIDS – Acquired Immunodeficiency Syndrome
HAART – Highly Active Antiretroviral Therapy
ART – Antiretroviral Therapy
PLWHIV – People Living with HIV
DM – Diabetes Mellitus
NCDs – Non-Communicable Diseases
WHO – World Health Organization
MRC – Medical Research Council

Source of funding

The study received no external funding.

Conflict of interest

The authors declare no conflict of interest.

Data availability

Data is available upon request from the author.

Author contributions

SDL: collected the data.
CE: supervised the study.

Informed consent

Written informed consent was obtained from all participants prior to their inclusion in the study. Participants were informed about the purpose of the study, procedures involved, potential risks and benefits, and their right to withdraw at any time without penalty.

Author biography

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