

Healthcare Experiences and Service Delivery Gaps for Pregnant Women Living with HIV in Kiryandongo Settlement Camp, Northern Uganda

Amir Kabunga¹, Samsom Udho², Maxson Kenneth Anyolitho³, Marvin Musinguzi⁴, Ann Grace Auma⁵, Viola Nalwoga¹, Eustes Kigongo⁴

¹Department of Psychiatry, Lira University, Lira City, Uganda; ²Department of Midwifery, Lira University, Lira City, Uganda; ³Department of Community Health, Lira University, Lira City, Uganda; ⁴Department of Environmental Health and Disease Control, Lira University, Lira City, Uganda; ⁵Department of Nursing, Lira University, Lira City, Uganda

Correspondence: Amir Kabunga, Lira University, P.O. Box, 1035, Lira City, Uganda, Tel +256777929576, Email amirkabs2017@gmail.com

Background: HIV-positive pregnant women in refugee settings face significant barriers to accessing quality maternal healthcare. In Uganda, Kiryandongo Settlement Camp, one of the largest refugee settlements, exemplifies these challenges with limited healthcare infrastructure, stigma, and socio-economic constraints affecting healthcare delivery. This study explores the healthcare experiences and service delivery gaps for HIV-positive pregnant women in the camp.

Materials and Methods: An exploratory qualitative research design was employed in Kiryandongo Settlement Camp, involving purposive sampling of 30 pregnant women living with HIV, 10 healthcare providers, and 5 key informants. Data were collected through in-depth interviews and key informant interviews.

Results: The findings revealed multiple barriers to healthcare access, categorized into three sub-themes: inadequate healthcare infrastructure, long waiting times and staff shortages, and stigma and discrimination. Participants reported frustration with the lack of medical supplies, inadequate facilities, and the impact of stigma on their willingness to seek care. Healthcare providers also acknowledged these challenges, noting limited resources and strained personnel as contributing factors. The most significant finding was the pervasive impact of stigma, which not only hindered service access but also contributed to a reluctance to engage with healthcare services, further affecting ART adherence.

Conclusion: This study highlights the critical need for improvements in healthcare infrastructure, policy interventions to reduce stigma, and increased support for healthcare providers in Kiryandongo Settlement Camp. Addressing these gaps is essential for enhancing ART adherence, maternal health outcomes, and the effectiveness of PMTCT programs in refugee settings. Despite the focus on a single site, the findings have broader implications for refugee health policy and service delivery in similar contexts.

Keywords: ART adherence, service delivery gaps, pregnant women living with HIV, refugee health, Kiryandongo settlement camp

Background

Globally, HIV remains a significant public health challenge, particularly among pregnant women. In 2023, an estimated 39.9 million [36.1 million–44.6 million] people were living with HIV, with 38.6 million [34.9 million–43.1 million] being adults aged 15 years or older.¹ Notably, 53% of all people living with HIV were women and girls, highlighting the disproportionate burden faced by females.¹ Pregnant women living with HIV face increased risks of adverse health outcomes, including maternal morbidity, mortality, and the possibility of mother-to-child transmission of the virus. Despite substantial progress in expanding access to antiretroviral therapy (ART), with approximately 30.7 million [27–31.9 million] people receiving treatment by the end of 2023,¹ critical gaps remain, particularly in resource-limited and humanitarian settings where access to comprehensive maternal and HIV services can be limited. Understanding healthcare experiences and service delivery gaps for pregnant women living with HIV is therefore essential to improving outcomes and closing persistent disparities in care.

Despite global efforts to curb HIV transmission, pregnant women living with HIV face unique challenges in accessing timely and comprehensive maternal healthcare services.^{2,3} These challenges are particularly pronounced in resource-limited settings such as refugee and settlement camps, where barriers such as inadequate healthcare infrastructure, stigma, and shortages of trained healthcare providers complicate service delivery.⁴ Studies indicate that pregnant women in these environments often experience delays in initiating ART, limited access to routine antenatal care, and challenges in adhering to prevention of mother-to-child transmission (PMTCT) protocols.⁵ These gaps pose significant risks to maternal and child health outcomes, contributing to higher rates of HIV transmission and adverse pregnancy-related complications.

Migrant and refugee populations are disproportionately affected by HIV due to multiple social and structural vulnerabilities, including health inequities and restricted access to healthcare services. A systematic review and meta-analysis by Santoso et al found that the pooled HIV prevalence ratio for foreign-born migrants was 1.70 times higher than that of native-born populations. Among specific migrant groups, refugees had a prevalence ratio of 2.37, undocumented people 3.98, and asylum seekers 54.79.⁶ These findings stress the heightened vulnerability of displaced populations to HIV, particularly in low-resource settings. However, the study also noted significant heterogeneity in HIV prevalence based on migrant type, country of origin, and study setting, emphasizing the need for context-specific interventions.⁶ Despite the known risks, the available literature on HIV among migrants and refugees remains limited, with most studies focusing on the general population rather than displaced communities.⁷ Reports from the United Nations High Commissioner for Refugees (UNHCR) and other global health organizations have highlighted the lack of comprehensive data on HIV prevalence among refugees, particularly pregnant women.⁸ This gap in research makes it difficult to design effective policies and interventions tailored to the unique needs of refugee populations.

In Uganda, refugee settlements such as Kiryandongo face persistent healthcare access barriers, which may further exacerbate the HIV burden among pregnant women living in these settings.⁹ Kiryandongo Settlement Camp, one of Uganda's largest refugee settlements, faces significant healthcare access barriers that may impact the quality of care for pregnant women living with HIV. While efforts have been made to improve maternal healthcare services, challenges related to service delivery, access to treatment, and overall healthcare experiences remain unclear. Understanding the lived experiences of HIV-positive pregnant women in Kiryandongo is crucial for identifying potential gaps in care and informing targeted interventions. This study is guided by the Social-Ecological Model (SEM), which considers the multiple levels of influence on individual health behaviors. The SEM framework acknowledges the interplay between individual, interpersonal, community, and societal factors in shaping healthcare access and outcomes.¹⁰ By applying this framework, the study aims to examine how structural factors (such as healthcare infrastructure and policies) and personal factors (such as stigma and ART adherence) interact to impact the healthcare experiences of pregnant women living with HIV in Kiryandongo.

Materials and Methods

Study Setting

This study was conducted at Panyadoli Health Center IV, a key health facility within Kiryandongo Refugee Settlement in Uganda. Panyadoli Health Center IV provides a range of inpatient and outpatient services, including antenatal care, family planning, HIV treatment, and health education, making it a crucial point of care for HIV-positive pregnant women in the settlement. Kiryandongo Refugee Settlement, located in Bweyale, Kiryandongo District, hosts a diverse population of over 111,450 refugees as of August 14, 2024, primarily from South Sudan, the Democratic Republic of the Congo, and other neighboring countries. Given the high number of displaced individuals relying on limited healthcare infrastructure, the settlement presents unique challenges in maternal healthcare access, HIV treatment adherence, and service delivery gaps.

Study Design

This study employed an exploratory research design to gain in-depth insights into the lived experiences of HIV-positive pregnant women in Kiryandongo Settlement Camp, focusing on their healthcare experiences and service delivery gaps. Given the complexity of healthcare access and the unique challenges faced by this vulnerable population, an exploratory approach allows for a flexible and open-ended investigation into their perceptions, barriers to care, and interactions with healthcare providers.

Study Participants and Sample Size Estimation

This study targeted pregnant women living with HIV aged 18 years and above and healthcare providers directly involved in their care. Additionally, key informants were included to provide broader insights into refugee healthcare services, policy implementation, and system-level challenges that impact service delivery. Pregnant women were the primary focus, given their unique vulnerability regarding maternal healthcare access and HIV treatment adherence. Healthcare providers offered frontline perspectives on the quality, availability, and challenges in service delivery. Key informants contributed contextual and policy-level understanding critical to interpreting structural healthcare barriers within the refugee setting. The principle of data saturation was applied, leading to the inclusion of 30 pregnant women living with HIV, 10 healthcare providers, and 5 key informants. Inclusion criteria comprised pregnant women living with HIV receiving antenatal care, healthcare providers offering maternal and HIV-related services, and key informants with expertise in refugee health services. Women unable to provide informed consent due to cognitive or health impairments were excluded. A brief assessment of cognitive and health impairments was made during the recruitment process to ensure eligibility.

Sampling Technique

A purposive sampling technique was used to recruit pregnant women living with HIV, healthcare providers, and key informants to ensure a comprehensive and relevant understanding of healthcare experiences and service delivery gaps in Kiryandongo Settlement Camp. Participants were intentionally selected based on their knowledge, experience, and role within the healthcare system or refugee health services. Healthcare providers were chosen for their direct interaction with the study population, while key informants provided system-wide perspectives on healthcare delivery and policy implementation challenges. The recruitment process involved approaching participants through community health workers and healthcare facility staff who facilitated initial contact with potential participants. Participants were invited to an information session about the study, after which they were given a consent form and time to decide whether to participate. The final sample size was guided by the principle of data saturation.

Data Collection Instruments

Data were collected through in-depth interviews and key informant interviews (KIIs). In-depth interviews explored personal experiences of pregnant women living with HIV regarding maternal healthcare access, treatment adherence, and challenges encountered. Healthcare providers were interviewed to capture their experiences with service provision and systemic constraints. KIIs were conducted with key informants to gather expert perspectives on healthcare infrastructure, programmatic challenges, and policy considerations affecting HIV care delivery in the settlement. Sample questions included: “Can you describe your experience accessing antenatal care while living with HIV?” and “What challenges have you faced in providing care to HIV-positive pregnant women?” These tools collectively ensured a multi-layered understanding of the healthcare experiences and systemic gaps.

Procedure

Face-to-face, semi-structured interviews were conducted by trained researchers familiar with the local context and fluent in the predominant languages of Kiryandongo Settlement Camp. The interview team included a psychologist (AK), one public health specialist (EK), and one social scientist (MK), all experienced in qualitative and refugee health research. One interviewer was female, and three were male. Given the sensitive nature of HIV and maternal health issues, interviews were conducted in private and quiet settings within Panyadoli Health Center IV or, where necessary, in confidential spaces within community centers. This approach ensured participants’ privacy, comfort, and trust throughout the interview process. Local leaders and CHWs were engaged during the preparatory phase to facilitate community entry and trust-building. All interviews were audio-recorded with participants’ consent and conducted in English or the participants’ preferred language, with translation provided as needed. To minimize biases such as social desirability bias, interviewers were trained to avoid leading questions and ensure that participants felt comfortable sharing honest responses. Prior to interviews, informed consent was obtained, and participants were briefed on the study’s objectives, risks, and benefits. Each interview lasted approximately 37 to 54 minutes.

Data Analysis

In our study, we employed Braun and Clarke's thematic analysis approach¹⁰ to systematically analyze the qualitative data collected from women living with HIV in Kiryandongo Settlement Camp. The analysis followed six structured steps, beginning with data immersion and transcription to ensure a deep understanding of the content and context. This initial phase allowed us to familiarize ourselves thoroughly with the data, capturing the nuances of participants' lived experiences.

Next, we generated initial codes to highlight key concepts, serving as labels for significant aspects of the data. We then searched for overarching themes by identifying recurring patterns aligned with our research objective, focusing on healthcare experiences and service delivery gaps. This involved an iterative process of reviewing and refining potential themes to ensure they accurately represented the participants' perspectives. Themes were validated against coded extracts, and once confirmed, we defined and described each theme in detail, assigning clear, descriptive names to clarify their meaning and scope. The integration of these themes into a cohesive narrative aimed to provide a comprehensive understanding of the challenges and opportunities within the healthcare system for women living with HIV in the settlement camp.

Our analysis was enriched by diverse perspectives, including the principal investigator and three experts in qualitative research, as well as collaborative workshops. We ensured data saturation by continuing data collection and analysis until no new themes emerged, thereby confirming the depth and comprehensiveness of our findings.

Rigor

To ensure the rigor of our study, we implemented robust measures aligned with Lincoln and Guba's criteria for qualitative research—credibility, dependability, confirmability, and transferability.¹¹

For credibility, we conducted regular team discussions, ensuring a collaborative environment that facilitated consensus-building and inclusive decision-making. The research team's diverse backgrounds enriched the analysis, and we actively addressed potential researcher biases during both data collection and analysis phases.

To enhance dependability, we conducted in-depth individual interviews in a safe and non-judgmental environment, encouraging participants to openly share their experiences. We employed enhanced probing techniques and open-ended questions to avoid premature conclusions, allowing participants to guide the discussion organically. By framing interviews as reciprocal conversations, we built trust, minimized power dynamics, and fostered authentic engagement.

Confirmability was achieved through methodological triangulation, incorporating perspectives from healthcare providers, women living with HIV, and CHWs to validate findings from multiple viewpoints. These rigorous measures collectively strengthened the reliability and trustworthiness of our study, enhancing its potential transferability to similar humanitarian and healthcare settings. Additionally, some participants were invited to review the transcripts and final report to ensure their views were accurately represented in the analysis.

Ethical Considerations

The study received ethical approval from the Lira University Research Ethics Committee (LUREC-2024-193). Participation was voluntary, with informed consent obtained from all participants prior to their involvement. Participants provided consent both verbally and by signing a consent form that clearly outlined the study's purpose, data collection procedures, participants' rights, and permission for the publication of anonymized responses and direct quotes. This process adhered to the principles of the Declaration of Helsinki and the Belmont Report. To ensure confidentiality, no personal identifiers were collected, and participants were assigned unique codes to maintain anonymity. Access to the study site and participants was granted by the Office of the Prime Minister and local authorities. The study also prioritized participants' well-being, particularly those experiencing distress, by offering referrals for counseling services to anyone needing mental health support during the study.

Results

Demographic Information

The study included a total of 45 participants to ensure a comprehensive understanding of healthcare experiences and service delivery gaps in Kiryandongo Settlement Camp. Among them were 30 pregnant women living with HIV, all

female, aged between 18 and 45 years. Additionally, 10 healthcare providers participated, comprising six females and four males, with ages ranging from 25 to 55 years. Furthermore, five key informants, including three females and two males aged 30 to 60 years, provided valuable insights (Table 1). This diverse representation allowed for a well-rounded analysis of the challenges and gaps in healthcare service delivery for women living with HIV in the settlement.

Themes

The thematic analysis revealed three major themes: barriers to healthcare access, challenges in art adherence and PMTCT services and coping strategies and community support.

Theme 1: Barriers to Healthcare Access

Participants' narratives revealed several barriers affecting their ability to access healthcare services in Kiryandongo Settlement Camp. These barriers were categorized into three key sub-themes: inadequate health infrastructure, long waiting times and limited staff, and stigma and discrimination.

Sub-Theme 1.1: Inadequate Health Infrastructure

Participants expressed frustration with the limited healthcare facilities available in the settlement. Many clinics lacked the necessary space, medical equipment, and essential supplies to cater to the high number of patients seeking care. Some healthcare providers also acknowledged the challenge of working in overcrowded and poorly resourced environments.

The clinic is too small, and sometimes we are turned away due to lack of space. Participant 4 (Pregnant Woman)

Echoing the concerns of pregnant women, healthcare providers also noted the challenges they faced due to insufficient infrastructure.

We don't have enough examination rooms, and sometimes we have to attend to patients in open areas, which compromises privacy. Healthcare Provider 3

This highlights how the lack of adequate infrastructure not only affects the quality of care for pregnant women living with HIV but also contributes to a feeling of neglect and frustration among both patients and healthcare workers.

The relationship between healthcare professionals and pregnant women living with HIV in Kiryandongo Settlement Camp can place considerable strain on health staff, contributing to burnout. These women are a high-needs group, requiring not only specialized care for HIV and pregnancy but also frequent support throughout their resettlement. Access to healthcare can vary depending on the individual needs of each woman, influencing the type of care she receives. Trust plays a crucial role in this dynamic; healthcare professionals are often seen as more than just providers of medical care but as reliable sources of broader support. One participant explained,

Women come to see a specific doctor not only for their health needs but also for guidance on housing and employment....., they trust the doctor for more than just health issues. Healthcare Provider 10

This trust in healthcare providers, while important, can contribute to the emotional and professional strain on staff, as they are expected to address a wide range of complex needs beyond healthcare.

Table 1 Demographic Information

Category	Number	Gender	Age Range
Pregnant Women Living with HIV	30	All Female	18–45 years
Healthcare Providers	10	6 Female, 4 Male	25–55 years
Key Informants	5	3 Female, 2 Male	30–60 years
Total Participants	45	–	–

Sub-Theme 1.2: Long Waiting Times and Limited Staff

Many participants reported experiencing long waiting times at healthcare facilities due to an insufficient number of healthcare workers. Pregnant women living with HIV noted that delays in receiving medical attention discouraged them from seeking care regularly.

We wait for hours to see a nurse, and sometimes we leave without getting treatment because the queue is too long. Participant 9 (Pregnant Woman)

In line with these concerns, a healthcare provider observed:

Sometimes, we have only two nurses attending to many patients, making it impossible to provide quality care. Healthcare Provider 6

This shortage of staff and the resulting long waiting times create a significant barrier to care, leaving pregnant women living with HIV feeling neglected and reluctant to access services regularly. The inefficiencies in the healthcare system not only contribute to poor service delivery but also worsen health outcomes, as women are left with limited opportunities for timely interventions and support.

Sub-Theme 1.3: Stigma and Discrimination

Stigma and discrimination within healthcare settings emerged as a major barrier to care for pregnant women living with HIV. Many women reported being treated differently once their HIV status was known. Some healthcare providers acknowledged that stigma continues to affect service delivery.

Some nurses look at me differently when they see my HIV records. They don't say anything, but their attitude changes. Participant 11 (Pregnant Woman)

This view was reinforced by a key informant who stated:

There is still stigma even among healthcare workers. Some staff are reluctant to provide services to HIV-positive mothers. Key Informant 2

In refugee communities in Uganda, particularly in settlement camps like Kiryandongo, the intersection of HIV and pregnancy compounds the stigma women face. This double burden can be overwhelming, as pregnant women living with HIV encounter both societal discrimination and significant barriers to healthcare access. As one healthcare provider noted:

Access to HIV care is often hindered by stigma related to both HIV and pregnancy. This stigma exists not only within the host population but also within migrant communities. Pregnant women with HIV often feel marginalized, which impacts their willingness to seek care and delays necessary treatment. This creates a complex challenge that significantly affects their health outcomes. Healthcare Provider 1

The stigma experienced by pregnant women living with HIV can discourage them from engaging with healthcare services, further exacerbating the gaps in care and hindering their ability to manage both their pregnancy and HIV effectively.

Theme 2: Challenges in ART Adherence and PMTCT Services

Under this major theme, participants highlighted various challenges affecting adherence to antiretroviral therapy (ART) and the implementation of prevention of mother-to-child transmission (PMTCT) services.

Sub-Theme 2.1: Language Barrier

A major obstacle to effective healthcare for pregnant women living with HIV in Kiryandongo Settlement Camp was the persistent language barrier between healthcare providers and patients. Miscommunication often hindered medication adherence and access to essential health information. The absence of trained interpreters in healthcare facilities made it difficult for many women to fully grasp medical instructions, leading to confusion and non-compliance with treatment plans as one participant shared:

There was no interpreter when they spoke to me. I struggled to understand what they were saying. Participant 7 (Pregnant Woman)

This challenge was further compounded by the diverse ethnic backgrounds of refugees in the camp, including those from the Democratic Republic of Congo, Rwanda, Kenya, and South Sudan, each speaking different languages. Without adequate language support, many women faced significant barriers to receiving proper care. Supporting this concern, a key informant highlighted:

We have patients from different countries, and many do not speak English or Swahili. Without interpreters, it is difficult to explain treatment options, follow-ups, and the importance of adherence. I believe some women do not talk their medication because they do not understand the instructions. (Key Informant 3)

This gap in communication not only affected adherence to antiretroviral therapy but also contributed to feelings of uncertainty and frustration among patients.

Sub-Theme 2.2: Lack of Psychosocial Support

Participants highlighted the critical need for enhanced psychosocial support services, particularly counseling, to address the emotional and psychological challenges faced by pregnant women living with HIV in Kiryandongo Settlement Camp. Many women expressed that access to structured counseling sessions would be instrumental in helping them manage their diagnosis and navigate the complexities of treatment during pregnancy. One participant shared her struggles:

I need more support, more support. someone to talk to because we feel alone in this journey. It would help to have someone to discuss my fears with. Participant 15 (Pregnant Woman)

The shortage of psychosocial support services was echoed by healthcare professionals working in the camp. A key informant stressed the importance of counseling in improving the overall well-being of pregnant women living with HIV but acknowledged existing gaps:

We provide counseling because it is essential, but we simply don't have enough trained staff to offer regular sessions. Some patients require specialized support that we currently lack, and I believe this gap needs urgent attention. Key Informant 3 (Healthcare Provider)

The absence of consistent psychosocial support exacerbates feelings of isolation and fear, undermining the overall effectiveness of HIV care and treatment in the camp.

Theme 3: Coping Strategies and Community Support

Sub-Theme 3.1: Social Support

Despite the many challenges they faced, pregnant women living with HIV in Kiryandongo Settlement Camp identified various coping mechanisms and support systems that helped them navigate their healthcare experiences. Family and peer support groups emerged as a crucial source of emotional encouragement, providing a sense of belonging, motivation to adhere to ART, and reinforcement to attend medical appointments.

Many women found their greatest source of support within their families, particularly from their mothers, who could relate to both the struggles of living with HIV and the realities of pregnancy as one woman shared:

With my mother, it is different... she understands more about what I'm going through. I truly rely on her—she is a great source of support. Participant 16 (Pregnant Woman)

Another participant emphasized the importance of peer support:

Being in a support group helps me stay strong and take my medication regularly.... when we meet and share our experiences, it helps us feel less isolated. Participant 19 (Pregnant Woman)

However, not all women had the same support system. One participant shared a particularly painful experience of abandonment after her diagnosis:

When I was tested, I was also found HIV positive. My husband was found negative, and he deserted us in the hospital. He reacted very negatively towards me. He abandoned me and my children. Participant 22 (Pregnant Woman)

These lived experiences highlight the complex realities faced by HIV-positive pregnant women in Kiryandongo Settlement Camp, shaped by healthcare barriers, stigma, and the struggle for daily survival in a refugee setting. Addressing these gaps in healthcare service delivery is crucial to ensuring better support systems for both mothers and their children.

Sub-Theme 3.2: Role of Community Health Workers

Community health workers played a vital role in bridging the healthcare gaps by providing essential support, including home visits, adherence reminders, and basic health education. Their involvement was particularly critical in ensuring that pregnant women living with HIV remained on treatment and followed medical recommendations. As one healthcare provider noted:

The health workers visit us at home, reminding us to take our medication and helping us understand how to stay healthy.
Participant 5 (Pregnant Woman)

A key informant further emphasized the impact of community health workers on treatment adherence:

Without the community health workers, many women would stop taking their medication. They keep us on track. Key
Informant 4

The presence of community health workers not only improved health outcomes but also helped foster trust between healthcare providers and the refugee community, ensuring that more women had access to the support they needed.

Discussion

The aim of this study was to explore the healthcare experiences and service delivery gaps for HIV-positive pregnant women in Kiryandongo Settlement Camp in Uganda, with the goal of informing policy and improving maternal health outcomes and ART adherence. The findings revealed three major themes: barriers to healthcare access, challenges in ART adherence and PMTCT services, and coping strategies and community support. Key barriers included inadequate healthcare infrastructure, long waiting times, limited staff, and stigma and discrimination. Participants also faced challenges with ART adherence, exacerbated by language barriers and the lack of psychosocial support. Despite these challenges, social and peer support, as well as the involvement of CHWs, played vital roles in helping women manage their health and adhere to treatment. The study highlights the urgent need for improvements in healthcare infrastructure, reduction of stigma, better language support, and enhanced psychosocial care to improve health outcomes for pregnant women living with HIV in refugee settings.

Our findings show that key barriers to healthcare access for pregnant women living with HIV in Kiryandongo Settlement Camp include inadequate healthcare infrastructure, long waiting times, limited staff, and stigma and discrimination. These barriers are consistent with the challenges identified in existing literature, where poor infrastructure and insufficient healthcare personnel are commonly reported in resource-limited settings.^{7,8} Long waiting times, as highlighted in our study, align with similar findings from other regions, where delays in care exacerbate health risks for both the mother and the child.¹² Stigma and discrimination were also prevalent, reflecting the ongoing social and cultural barriers faced by pregnant women living with HIV, which have been widely documented in previous studies.^{2,13} Addressing the gaps in infrastructure, staffing, and stigma is essential to enhance the accessibility and quality of care, ultimately improving maternal and child health outcomes in such vulnerable settings.

Our results indicate that participants faced significant challenges with ART adherence, which were exacerbated by language barriers and the lack of psychosocial support. These findings are in line with existing literature, which highlights that language barriers can severely limit understanding of treatment regimens, resulting in reduced adherence to ART, particularly in refugee and settlement settings.¹⁴ Studies have shown that when patients are unable to communicate effectively with healthcare providers, they are more likely to misunderstand their treatment plans, leading to non-adherence.¹⁴ Additionally, the absence of psychosocial support, such as counseling or peer support, is a well-documented barrier to adherence, as it addresses the emotional and psychological difficulties faced by individuals living with HIV.¹⁵ Our study stresses how these factors collectively contribute to poor health outcomes for pregnant women living with HIV. Our findings suggest that improving ART adherence in such contexts requires the integration of language support services and robust psychosocial support programs. These interventions are critical in helping

individuals understand their treatment regimens and cope with the psychological burdens of living with HIV, ultimately improving health outcomes for both mothers and their babies.

Our results reveal that despite the challenges, social and peer support, as well as the involvement of CHWs, played vital roles in helping pregnant women living with HIV manage their health and adhere to treatment. These results align with existing literature that emphasizes the positive impact of social support and community engagement in improving health outcomes for people living with HIV.¹⁵ Peer support, particularly in settings where stigma is prevalent, has been identified as a crucial factor in encouraging adherence to ART, as it provides emotional encouragement and practical advice from individuals who share similar experiences.¹⁶ The involvement of CHWs has also been widely recognized as an effective strategy for improving healthcare access and treatment adherence, especially in underserved and resource-poor environments. However, while these support systems were found to be beneficial, the literature also suggests that their effectiveness is often limited by the availability of training and resources for CHWs.¹⁶ In Kiryandongo, the findings highlight that while these support mechanisms were crucial, they were not a comprehensive solution to the barriers faced by the women. The implications of these findings suggest that strengthening social support networks and investing in training and resources for CHWs could significantly improve healthcare delivery for pregnant women living with HIV, enhancing both treatment adherence and overall health outcomes in similar settings.

Strengths and Limitations of the Study

This study provides a comprehensive and in-depth exploration of the healthcare experiences and service delivery gaps for HIV-positive pregnant women in Kiryandongo Settlement Camp, utilizing a qualitative approach. The diverse representation of participants, allows for a well-rounded analysis of the issues faced within the settlement. While the study offers valuable insights, it is limited by its focus on a single refugee settlement, Kiryandongo, which may not fully represent the experiences of HIV-positive pregnant women in other refugee camps across Uganda or other African countries. The sample size of 45 participants, though adequate for qualitative research, may not capture the full diversity of experiences within the population, particularly given the varied ethnic backgrounds and languages spoken by refugees in the camp. Language barriers may have impacted the depth of responses in interviews, as some participants were not fluent in English, and translation may have introduced nuances that were lost during the process. Furthermore, the study relies on self-reported data from participants, which may be influenced by social desirability bias or the reluctance to disclose sensitive information, such as experiences with stigma or adherence challenges. The limitations of this study also include the potential lack of generalizability to other refugee settings due to the unique socio-economic and political context of Kiryandongo. To address this limitation, triangulation of data sources was used by including perspectives from multiple stakeholders such as healthcare providers and key informants. Additionally, member checking was conducted with a subset of participants to validate findings and ensure accuracy of interpretations.

Conclusion

This study highlights significant barriers to healthcare access and ART adherence among HIV-positive pregnant women in Kiryandongo Settlement Camp, highlighting the critical need for targeted interventions to improve healthcare delivery in refugee settings. The findings suggest that enhancing healthcare infrastructure, addressing stigma, providing more tailored educational outreach, and supporting community health workers are essential strategies for improving outcomes. However, there is a need for future research to explore the effectiveness of these proposed interventions in refugee settings. Additionally, expanding this study to include other refugee camps in Uganda or across the African continent would help determine whether the findings are consistent in different contexts and settings. Further exploration of the role of community health workers in improving healthcare delivery could also yield valuable insights for scaling up effective interventions.

Author Contributions

All authors made a significant contribution to the work reported, whether that is in conception, study design, execution, acquisition of data, analysis, and interpretation, or all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agreed to be accountable for all aspects of work.

Disclosure

The authors report no conflicts of interest in this work.

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