

Navigating Pregnancy with HIV: Challenges and Experiences of Women in Uganda

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ABSTRACT

Pregnant women living with HIV (WLWH) in Uganda face multifaceted challenges that span medical, psychosocial, structural, and cultural domains. Despite advancements in antiretroviral therapy (ART) and prevention of mother-to-child transmission (PMTCT) programs, barriers such as stigma, discrimination, disclosure fears, intimate partner violence, and limited healthcare infrastructure persist. This review explores the lived experiences of WLWH during pregnancy, emphasizing the interplay between socio-cultural dynamics and healthcare engagement. It identifies critical obstacles, including poor integration of services, inadequate counseling, and socio-economic hardships that undermine adherence and health outcomes. The coping strategies and support networks women employ highlight resilience but also the need for systemic improvements. Policy and programmatic recommendations stress enhancing confidentiality, respectful care, and counseling quality, especially for late antenatal care attendees. Integrating HIV, family planning, and maternal health services, addressing intimate partner violence through multisectoral approaches, and expanding psychosocial support are vital. Tailored adolescent-friendly interventions are also essential. A holistic, person-centered approach that addresses medical, social, and structural factors is imperative to improve maternal and child health outcomes among WLWH in Uganda.

Keywords: Pregnant women, HIV, Uganda, antiretroviral therapy, PMTCT, stigma, disclosure.

INTRODUCTION

In Uganda, as in much of Sub-Saharan Africa, the burden of HIV remains a significant public health challenge, particularly among women of reproductive age [1]. According to the Uganda Population-based HIV Impact Assessment (UPHIA) 2020, women continue to experience a higher prevalence of HIV than men, with women accounting for more than half of all people living with HIV (PLHIV) in the country. Among these women, a considerable proportion are pregnant, thereby introducing a complex interplay between HIV management and maternal health [2]. The past two decades have witnessed substantial advancements in HIV care, notably through the scale-up of antiretroviral therapy (ART) and prevention of mother-to-child transmission (PMTCT) programs [3]. Uganda's Ministry of Health, in collaboration with global health partners such as UNAIDS, PEPFAR, and the WHO, has made commendable efforts to improve access to maternal and child health services. Interventions such as Option B+, a lifelong ART regimen initiated at HIV diagnosis regardless of CD4 count, have significantly reduced vertical transmission rates [4]. Despite this progress, pregnant women living with HIV (WLWH) continue to encounter numerous and often overlapping barriers throughout the course of pregnancy. These challenges are not only medical in nature but also psychosocial, structural, and deeply embedded in socio-cultural dynamics [5]. WLWH may experience stigma and discrimination from healthcare providers, communities, and even family members. Fear of disclosure, lack of partner support, food insecurity, poverty, and inadequate healthcare infrastructure further complicate adherence to ART and engagement in prenatal services. Cultural beliefs and gender power imbalances also influence health-seeking behavior. In many Ugandan communities, male partners play a dominant role in decision-making, including access to health services. Pregnant women who wish to attend antenatal care or adhere to treatment protocols may lack autonomy, particularly if disclosure of their HIV status risks domestic violence or abandonment [6]. While Uganda has made strides in integrating HIV services within maternal health platforms, a critical gap remains in understanding and addressing the lived experiences of WLWH

during pregnancy. This study seeks to explore these experiences, not only through a biomedical lens but with an appreciation of the broader socio-structural context in which these women live [7]. Pregnancy in the context of HIV poses unique and compounded challenges for women in Uganda. While ART and PMTCT interventions have become more accessible, utilization and adherence among pregnant WLWH remain suboptimal in several regions. Many of these women navigate their pregnancies within environments characterized by limited access to comprehensive care, persistent stigma, and socio-economic hardships [8]. There is also a disconnect between policy-level improvements in HIV maternal health services and the on-the-ground realities faced by expectant WLWH. Health systems often fail to address the psychosocial burdens associated with HIV during pregnancy. For instance, the fear of being recognized at HIV clinics deters many women from seeking care, leading to missed appointments and compromised treatment outcomes [9]. Furthermore, existing research tends to focus on quantifiable health outcomes such as viral suppression and PMTCT success rates, with limited qualitative inquiry into women's narratives and perceptions. Understanding these lived experiences is essential for tailoring interventions that are not only clinically effective but also socially and culturally responsive [10]. This gap in literature and practice highlights the need for a more holistic approach to maternal care for WLWH, one that centers their voices, acknowledges the multiple dimensions of vulnerability, and leverages local context to drive policy and practice. The specific objectives of this study are designed to offer a comprehensive understanding of the unique challenges faced by pregnant women living with HIV (WLWH) in Uganda. Firstly, the study seeks to explore their lived experiences, shedding light on how they access, utilize, and adhere to HIV-related and maternal healthcare services during pregnancy. This exploration will help to uncover the multifaceted realities these women face, including how health systems, personal circumstances, and community dynamics shape their care experiences. Secondly, the research aims to identify critical barriers, medical, psychosocial, structural, and cultural, that hinder effective healthcare-seeking behavior among WLWH. These barriers may include stigma, limited healthcare infrastructure, transportation challenges, lack of social support, and harmful gender norms. Thirdly, the study will examine the coping strategies and support networks that women draw upon to navigate the intersectional challenges of pregnancy and HIV, including informal community support, religious faith, or peer networks. Fourth, it will assess the quality and responsiveness of Prevention of Mother-To-Child Transmission (PMTCT) and maternal health services from the women's perspectives, highlighting areas of both satisfaction and systemic failure. Finally, based on the findings, the study will propose actionable recommendations aimed at improving health service delivery, influencing policy decisions, and strengthening community-based support systems for WLWH. These objectives are aligned with the overarching goal of promoting equity, person-centered care, and empowerment by amplifying the voices of women whose experiences are often marginalized in public health discourse. This study not only contributes to knowledge but also has the potential to inform more effective, culturally sensitive, and rights-based approaches to maternal HIV care in Uganda.

Stigma and Discrimination

Stigma and discrimination remain major barriers to HIV care for women, particularly during pregnancy and postpartum. In clinical settings, enacted stigma manifests through overtly discriminatory behaviors by healthcare providers [11]. Women frequently report experiences such as being publicly identified as HIV-positive, separated from other patients during antenatal visits, or subjected to coercive practices like mandatory pill ingestion in front of staff. These actions not only violate patient dignity and autonomy but also foster fear, mistrust, and disengagement from essential healthcare services (pubmed.ncbi.nlm.nih.gov; onlinelibrary.wiley.com). Outside clinical settings, community and self-stigma exacerbate these challenges. Anticipated gossip, blame, and cultural shaming, especially in societies where HIV is equated with promiscuity, moral failure, or poor parenting, discourage women from disclosing their status, even to close family members or partners. This secrecy often results in poor adherence to treatment and missed opportunities for support. Additionally, pregnant adolescents living with HIV face a particularly harsh form of "double stigma," being judged both for their youth and their HIV status. These young women often experience heightened social exclusion and emotional distress, which further impedes their access to maternal and HIV care (dovepress.com). Addressing all layers of stigma, structural, social, and internalized, is critical to improving health outcomes and ensuring women living with HIV receive dignified, nonjudgmental care [12].

Disclosure Dilemmas: Timing, Partner Dynamics, and Systemic Challenges

The process of disclosing an HIV-positive status to a sexual partner is fraught with complex emotional, relational, and systemic dilemmas. One of the most significant challenges revolves around timing and the dynamics between partners. While disclosure to spouses tends to increase over time, often associated with improved antiretroviral therapy (ART) adherence and greater emotional and logistical support, fear remains a critical barrier. Many women delay or avoid disclosure due to concerns about intimate partner violence (IPV), being abandoned, or being accused of infidelity [13]. These fears are particularly pronounced in settings where gender inequality, economic dependency, and stigma are prevalent, making disclosure a potentially dangerous or destabilizing act. Compounding

this is the limited support offered by health systems, particularly within antenatal care (ANC) settings. In many cases, especially for women who present late in pregnancy, HIV counseling is rushed, leaving little time for thorough emotional preparation or the development of personalized disclosure strategies. This hurried approach undermines women's ability to process their diagnosis, plan safe disclosure, and access follow-up psychosocial support. Without adequate preparation and follow-through, women are often left to navigate the fallout of disclosure alone, heightening their vulnerability and weakening the broader public health impact of HIV testing and treatment initiatives [14].

Intimate Partner Violence & Economic Coercion

Intimate partner violence (IPV) remains a significant barrier to women's health and autonomy, particularly in the context of HIV and reproductive health. Numerous studies have documented high rates of physical, emotional, and sexual violence experienced by women, especially following the disclosure of their HIV status or in cases of unintended pregnancy [15]. Such disclosures often trigger mistrust, blame, and abuse from partners, further compounding the emotional and physical toll on women already dealing with a chronic illness or an unplanned pregnancy. Economic coercion is a particularly insidious form of control in these relationships. Many women, especially those in low-income settings, are economically dependent on their partners for basic needs such as food, shelter, healthcare, and childcare. This financial dependency forces them to remain in abusive relationships, tolerate mistreatment, and endure repeated trauma out of fear of losing access to essential resources. Ultimately, IPV and economic coercion perpetuate cycles of vulnerability, disempowerment, and poor health outcomes for women [16].

Psychosocial Distress & Mental Health

Women living with HIV/AIDS often experience profound psychosocial distress that significantly impacts their emotional well-being and ability to engage in consistent healthcare. Many report persistent feelings of anxiety, guilt, and shame, and fear emotions rooted in concerns about their baby's health, potential transmission of the virus, social stigma, and the uncertainty of their futures [17]. These emotional challenges are particularly intense during pregnancy and the postpartum period, when maternal responsibilities intersect with fears of discrimination and health-related outcomes. The stigma associated with HIV can lead to social isolation, secrecy, and strained relationships, further exacerbating psychological distress. Additionally, women may internalize guilt about their HIV status, leading to depressive symptoms and reduced self-worth. This emotional turmoil not only diminishes mental health but can also interfere with adherence to antiretroviral therapy (ART), clinic attendance, and overall care engagement. Addressing these psychosocial dimensions through counseling, support groups, and integrated mental health services is essential for improving health outcomes.

Structural & Health System Barriers

Structural and health system barriers significantly hinder the delivery of integrated sexual and reproductive health services, particularly for women living with HIV (WLWH) in many low-resource settings. Poor infrastructure and a shortage of trained health professionals compromise service quality and confidentiality [18]. Many facilities are overcrowded, lack privacy, and have insufficiently trained staff in areas such as family planning, HIV counseling, and long-term contraceptive methods. Inadequate integration between HIV care and reproductive health services often results in missed opportunities to provide contraception, contributing to high rates of unintended pregnancies among WLWH. Furthermore, accessibility remains a critical issue. Geographic distance to health facilities, high transportation and service costs, and negative or judgmental attitudes from healthcare providers deter many women from seeking essential services such as antenatal care (ANC). These barriers collectively limit women's ability to access timely, respectful, and comprehensive care, thereby exacerbating health disparities and undermining public health goals.

Coping Mechanisms & Support

Women living with HIV employ a range of coping mechanisms and support systems to navigate the emotional, social, and health-related challenges they face, particularly during pregnancy and motherhood. Access to antiretroviral therapy (ART), especially effective regimens like dolutegravir, instills a sense of optimism, empowering women with the hope of giving birth to HIV-negative children [19]. This medical assurance significantly reduces fear and promotes adherence. Equally important are social support networks mothers, sisters, and aunts often play key roles by offering emotional support, reminding women to take medication, assisting with transport to clinics, and helping them manage stigma and isolation. In addition to external support, many women adopt self-coping strategies such as relying on faith and prayer, maintaining confidentiality about their HIV status, attending peer support groups, or seeking care in distant clinics to avoid disclosure. These strategies collectively foster resilience, enhance treatment retention, and contribute to improved psychosocial well-being among women living with HIV.

Implications for Policy and Programming

Effective policy and programming must prioritize strengthening confidentiality and respectful care within maternity settings. This involves comprehensive training for healthcare workers to eliminate public identification of clients and coercive practices, fostering an environment of trust and dignity for pregnant women, especially those living with HIV. Enhancing the quality of counseling services is equally crucial, with a focus on late antenatal care (ANC) attendees [20]. This includes providing guided support for disclosure and actively involving male partners to improve health outcomes. Scaling up integrated health services—combining family planning (FP), HIV care, and ANC is essential to reduce unintended pregnancies and improve maternal and child health. Addressing intimate partner violence (IPV) requires a multisectoral approach that incorporates routine screening, well-coordinated referral systems, and robust legal protections for survivors. Empowering peer and family support networks by leveraging organizations such as TASO, Village Health Teams (VHTs), and community-led groups can strengthen social support and adherence to treatment. Additionally, psychosocial and mental health services need to be expanded through increased counseling availability, mobile outreach initiatives, and systematic mental health screening. Lastly, adolescent-friendly interventions tailored to the complex needs of pregnant teens living with HIV are critical to ensuring comprehensive care and improving long-term health outcomes [21].

CONCLUSION

This review highlights the complex challenges faced by pregnant women living with HIV in Uganda, emphasizing the need for comprehensive, culturally sensitive approaches to maternal HIV care. Despite advancements in antiretroviral therapy and PMTCT programs, many women continue to grapple with stigma, discrimination, disclosure fears, intimate partner violence, and psychosocial distress. Structural barriers within the healthcare system, such as limited integration of services, inadequate counseling, and poor infrastructure, further hinder effective care. Women's coping mechanisms, including social support networks and personal resilience, play a vital role in navigating these challenges but are insufficient without systemic improvements. The findings underscore the importance of policy and programming interventions that strengthen confidentiality, respectful care, and counseling quality, especially for late antenatal attendees. Integrated service delivery combining HIV care, family planning, and maternal health is crucial to reducing unintended pregnancies and improving outcomes. Multi-sectoral responses to intimate partner violence and expanded psychosocial support services are also essential. Tailored adolescent-friendly interventions remain critical to address the unique needs of young pregnant women living with HIV. Overall, a holistic, person-centered approach that addresses medical, social, and structural dimensions is vital for improving health and well-being among this vulnerable population.

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