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Patient Experiences in HIV Care: A Qualitative Review from Ugandan Hospitals

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ABSTRACT

Ugandan HIV services have expanded rapidly, improving access and clinical outcomes; however, this review indicates that patient experience remains uneven, particularly in hospital-based settings. Reported problems cluster around stigma, confidentiality breaches, weak communication, and fragmented continuity of care, amplified by congestion, limited space, and hierarchical structures. Knowledge gaps persist because many studies under-sample groups with distinct pathways and disclosure vulnerability, including adolescents, men, pregnant and postpartum women, and key populations. We call for in-depth qualitative work that centers lived experience and explains how context shapes perceived respect, privacy risks, waiting time for care, and follow-up support. Comparative research contrasting hospitals with lower-level health centers is needed to clarify where experiences diverge and why. Moving beyond description, implementation research should test scalable solutions privacy-by-design layouts, improved patient flow, and appointment, triage, or differentiated service-delivery models to reduce congestion and inadvertent disclosure. Finally, routine quality improvement requires standardized measurement: develop and validate Ugandan, language-appropriate patient-reported experience measures and embed them in facility monitoring to guide redesign, strengthen trust, improve retention, and advance equitable outcomes.

Keywords: HIV care, patient experience, qualitative, Uganda, stigma, confidentiality, adherence, retention, person-centered care

INTRODUCTION

Uganda has achieved major gains in HIV control over the past two decades, driven by expanded access to antiretroviral therapy (ART), improved viral load monitoring, and program innovations such as differentiated service delivery (DSD). These efforts have contributed to reduced HIV-related morbidity and mortality, improved survival, and stronger public confidence in HIV services [1]. However, progress in clinical coverage does not automatically translate into sustained outcomes across all patient groups and service settings. Persistent gaps remain in retention in care, consistent adherence, timely viral suppression, and equitable access to patient-centered services. Especially among adolescents and young people, pregnant and postpartum women, men, key populations, and rural patients who often enter care through referral pathways to hospitals [2].

Importantly, HIV care is not only about the availability of medicines and laboratory tests; it is also about how people experience the health system over time. The "patient experience" includes what patients perceive and report about communication, respect, confidentiality, waiting time, stigma, navigation of service points, physical environment, provider attitudes, and the responsiveness of care to their lived realities [3]. These experiences are not "soft" outcomes or optional extras. They are mechanisms that shape trust, influence care-seeking behavior, and determine whether clients remain engaged long enough to achieve and sustain viral suppression. When patients feel listened to, protected from stigma, and treated with dignity, they are more likely to return for appointments, disclose challenges, and collaborate in treatment planning [4]. Conversely, when patients anticipate humiliation, breaches of privacy, or dismissive treatment, they may delay visits, miss refills, disengage silently, or shift to informal and inconsistent care pathways outcomes that undermine both individual health and public health goals [5].

Hospitals occupy a distinctive position within Uganda's HIV ecosystem. Unlike lower-level health facilities that may offer more stable continuity with familiar staff and community-based follow-up, hospitals function as referral centers

for complex and high-volume care. They often manage advanced HIV disease, treatment failure, comorbidities such as tuberculosis (TB), mental health conditions, and non-communicable diseases (NCDs), and complicated cases requiring multidisciplinary services [6]. Hospitals also receive patients who have experienced treatment interruption and need re-initiation support. This makes the hospital setting clinically critical—but also operationally demanding. Patients frequently navigate multiple service points (triage, clinician review, laboratory, pharmacy, counseling, and records), sometimes in congested environments with long queues and variable appointment systems. These characteristics intensify the risk of poor experiences, particularly those related to waiting times, fragmentation of care, unclear communication, and perceived neglect [7].

Confidentiality is a central concern in HIV care, and hospital environments may heighten vulnerability to breaches. While hospitals can feel more anonymous—potentially protecting patients who fear being recognized in local clinics they are often crowded and structured in ways that require repeated movement between clinics and offices. In such contexts, privacy may be compromised through public calling of names, open counseling spaces, visible patient files, or queues that inadvertently reveal HIV status [8]. Fear of unintended disclosure can discourage timely attendance and lead to missed appointments or avoidance of particular service points such as viral load testing, counseling, or ART refills. For vulnerable groups adolescents, key populations, and women in pregnancy/postpartum periods these issues intersect with broader social risks, including stigma, gendered power dynamics, financial dependency, and mobility constraints [9].

Uganda's scale-up of DSD has aimed to reduce patient burden and improve outcomes by tailoring service intensity to clinical stability and patient preference. Yet, the extent to which DSD principles are consistently implemented in hospitals and whether patients perceive services as truly differentiated and patient-centered remains an important question. Hospitals may prioritize biomedical targets and throughput under pressure, sometimes at the expense of interpersonal care and responsiveness [10]. In addition, structural constraints such as staffing shortages, high patient loads, stock management challenges, and limited space can distort intended models of care. Understanding how patients experience hospital HIV care, and what they identify as supportive or harmful, is therefore essential for translating policy reforms into lived improvements at the service delivery level [11].

Qualitative research is uniquely positioned to illuminate these realities. While routine program data capture retention rates, viral suppression, and appointment adherence, they often fail to explain why patients disengage, what they fear, what motivates their persistence, and how service organization shapes their decisions. Qualitative evidence provides insight into patient meanings, perceptions, and priorities, revealing the relational and contextual drivers that quantitative indicators alone cannot capture. A focused review of qualitative findings from Ugandan hospitals can therefore generate actionable lessons for quality improvement, stigma reduction, confidentiality protection, and more humane, effective service delivery [12].

Despite Uganda's major gains in expanding ART access and strengthening viral load monitoring, retention in care and sustained viral suppression remain uneven, particularly among vulnerable groups and patients managed in hospital settings. Hospitals are expected to provide complex, referral-level HIV services, manage comorbidities, and ensure continuity for patients with advanced disease or prior treatment interruption, yet the hospital environment often creates barriers that weaken long-term engagement. Congestion, fragmented service points, long waiting times, and perceived or actual confidentiality breaches can generate negative patient experiences that erode trust, discourage timely attendance, and contribute to missed appointments, poor adherence, and disengagement. However, patient experience is frequently under-emphasized in routine performance monitoring, where attention tends to focus on clinical outcomes and service outputs rather than the service mechanisms that sustain those outcomes. When patient perspectives are not systematically synthesized and translated into practical improvements, avoidable failures such as disrespectful communication, unclear navigation systems, inconsistent counseling, and weak privacy protections may persist, reinforcing inequities and preventable treatment interruptions. This review therefore aims to synthesize qualitative evidence on patient experiences of HIV care in Ugandan hospitals by identifying supportive and harmful aspects of service delivery, clarifying how these experiences influence trust, care-seeking, adherence, and retention, and consolidating actionable, feasible service-level changes. The review is significant because it can inform patient-centered strategies to improve retention and viral suppression; guide hospital-specific quality improvement suited to referral realities; strengthen confidentiality and stigma reduction through redesign of patient flow and communication; highlight where hospital systems unintentionally disadvantage adolescents, pregnant/postpartum women, men, key populations, and rural referrals; support effective implementation of differentiated service delivery at referral level; and propose priority areas and indicators for future research and routine patient-experience monitoring to sustain respectful, confidential, accessible, and equitable HIV care.

Review Approach

This review uses a narrative, qualitative approach to synthesize evidence on how people living with HIV (PLHIV) experience hospital-based HIV care in Uganda. The evidence base is drawn primarily from qualitative studies conducted in Ugandan hospitals and hospital-affiliated HIV clinics, including in-depth interviews, focus group

discussions, ethnographic observations, and qualitative components embedded within mixed-methods designs. Conceptually, the review prioritizes patient perspectives across the HIV care continuum, capturing experiences of HIV testing and diagnosis, linkage to care, ART initiation, follow-up visits, viral load monitoring, counseling encounters, pharmacy services, and access to integrated or differentiated hospital services. Particular attention is paid to patient-reported barriers and facilitators that shape engagement with services, adherence to ART, and long-term retention in care, including interpersonal, organizational, and structural influences. Analysis follows a thematic synthesis framework: first, patient narratives and reported experiences are systematically coded; second, related codes are clustered into descriptive themes that summarize recurring patterns; and third, higher-order analytical themes are developed to interpret how these experiences connect to dimensions of care quality and downstream outcomes for PLHIV in hospital settings.

Thematic Findings

Across the thematic findings, patients portray hospital-based HIV care as a demanding, repetitive routine shaped as much by system design as by individual effort. Accessing ART is commonly described as a cycle of transport costs, pre-dawn departures, long queues, and multiple service stops triage, counseling, clinician review, laboratory, and pharmacy often in a fragmented flow that offers little guidance and results in missed steps, repeat visits, and physical exhaustion [13]. Even where ART is "free," the real price of care includes lost work time, childcare arrangements, and food costs during full-day clinic visits, with the burden falling hardest on those who are ill, pregnant, elderly, or traveling long distances. This "treatment burden" matters because it quietly fuels missed appointments, forces patients to invent excuses for prolonged absences, and can lead to silent disengagement rather than open dropout [14]. Within this context, the quality of health worker–patient relationships become pivotal: patients consistently equate "good care" with respect, empathy, and clear communication. When providers greet patients, listen attentively, explain ART, side effects, and viral load results in plain language, and encourage rather than punish lapses, trust grows and patients feel safer disclosing barriers. Conversely, scolding, harsh language, judgment about sexuality, pregnancy, alcohol use, or repeated infections, and rushed consultations generate fear and avoidance, undermining adherence, knowledge and willingness to return after interruptions. Stigma and confidentiality anxieties further shape engagement, often through spatial and procedural cues such as HIV-only queues, distinct waiting areas, labeled files, loud name-calling, visible pill bottles, or staff talk that risks involuntary disclosure [15]. Some patients mitigate this by attending distant facilities, trading higher transport costs for privacy. Structural constraints stock-outs, substitutions, staff shortages, lab delays, and overcrowding compound these pressures and are frequently interpreted as neglect, weakening perceived care quality. Yet clinics also serve as psychosocial anchors: peer networks and expert clients can create belonging, normalize living with HIV, and offer practical adherence strategies, though gaps remain in mental health support and in youth- and male-friendly services [16]. Finally, adherence challenges are framed less as "motivation problems" and more as daily realities side effects, food insecurity, competing responsibilities, alcohol-related environments, treatment fatigue, and pill concealment signaling that effective counseling must address transport, food, privacy, and mental health alongside biomedical education, while system improvements such as streamlined flow, clear signage, spaced appointments, fast-tracks, and DSD models can reduce visit frequency and clinic congestion.

Conceptual Model: How Patient Experience Shapes Outcomes

Across studies, patient experience shapes clinical outcomes through a set of connected behavioral and psychosocial pathways that ultimately determine engagement and adherence. First, trust and perceived respect from health workers strengthen the patient–provider relationship, making patients more willing to disclose challenges, return for follow-up, and re-engage after missed visits rather than dropping out silently. Second, confidence in confidentiality reduces fear of unwanted disclosure, which lowers care avoidance and supports consistent clinic attendance [17]. Third, the treatment burden, including transport costs, waiting time, clinic schedules, and regimen complexity, creates practical barriers that predict missed appointments and gradual disengagement, even when motivation is high. Fourth, meaningful communication improves ART literacy by clarifying dosing, side effects, and the purpose of monitoring, enabling patients to manage symptoms early and understand viral load results as feedback for progress. Finally, psychosocial support from providers, peers, or family improves coping and problem-solving, reduces internalized stigma, and helps patients build stable adherence routines [18]. Together, these pathways show that patient experience is not a "soft" outcome: it actively drives retention, adherence behaviors, and informed self-management, which then influence downstream biomedical markers and overall treatment success.

Implications for Practice in Ugandan Hospitals

In Ugandan hospitals, strengthening HIV service quality requires practical changes that patients can feel in every interaction and visit. Person-centered care (PCC) should be treated as a core quality strategy, with staff consistently demonstrating simple but high-impact behaviors such as greeting patients warmly, listening actively, and clearly explaining clinical decisions. Patients also value non-judgmental conversations about adherence, where providers avoid blame and instead engage in shared problem-solving around common barriers like transport costs, stigma, unstable food access, and competing family responsibilities [19]. At the system level, hospitals can reduce clinic

burden through differentiated service delivery: expanding multi-month dispensing for stable patients, introducing fast-track refill options, separating "stable refill" queues from "clinician review" lines, and using appointment systems that spread attendance across days and hours to reduce congestion and waiting times. Confidentiality must be protected by design, not only by policy where feasible; de-label HIV clinic spaces, adopt neutral clinic names and shared waiting areas, and use discreet numbering systems rather than calling out names or conditions. Regular staff refresher training should reinforce confidentiality, respectful communication, and patient dignity. Results communication also needs strengthening: viral load testing should be routinely explained in plain language, including what results mean for health and transmission risk, and patients should leave with clear follow-up plans (when to return, what warning symptoms require urgent care, and whom to contact) [20]. Simple handouts in local languages can reduce confusion and improve recall. Finally, integrating mental health and social support is essential: brief screening for depression and anxiety, clear referral pathways, supervised peer-support ("expert client") programs, and linkage to social protection or community resources can improve retention, adherence, and overall wellbeing.

Research Gaps and Future Directions

Key research gaps remain in understanding and improving patient experience within Ugandan HIV services, especially in hospital settings. Future work should prioritize qualitative studies that capture nuanced perspectives of underrepresented groups adolescents, men, pregnant and postpartum women, and key populations whose needs, stigma exposures, and care pathways may differ substantially from the general adult population. In parallel, comparative research is needed to distinguish how experiences vary between hospitals and lower-level health centers, including differences in waiting times, confidentiality risks, provider communication, continuity of care, and perceived respect [20]. Beyond describing problems, studies should move toward implementation research that tests feasible service-delivery solutions, such as privacy-by-design clinic layouts, optimized patient flow, and appointment or triage systems that reduce congestion and inadvertent disclosure. Finally, routine quality improvement would benefit from standardized measurement: developing and validating patient-reported experience measures (PREMs) tailored to Ugandan HIV contexts, languages, and stigma realities, then integrating these tools into regular monitoring at the facility level [21]. Together, these directions can generate actionable, context-specific evidence to guide redesign of services, strengthen trust, and improve retention and outcomes across diverse patient groups.

CONCLUSION

Ugandan HIV services have expanded access and improved clinical outcomes, yet this review shows that patient experience, especially in hospital-based care, remains uneven and insufficiently understood. Evidence gaps persist around how stigma, confidentiality, communication quality, and care continuity are shaped by congested environments and hierarchical service structures. Priority should shift toward in-depth qualitative work that foregrounds the lived realities of underrepresented groups, including adolescents, men, pregnant and postpartum women, and key populations, whose pathways and vulnerability to disclosure may differ markedly from the general adult population. Equally important is comparative research that explicitly contrasts hospitals with lower-level health centers to clarify where and why experiences diverge in waiting time, privacy risks, perceived respect, and follow-up support. Moving beyond problem description, implementation research is needed to test pragmatic, scalable solutions privacy-by-design clinic layouts, improved patient flow, and appointment, triage, or differentiated service-delivery approaches that reduce congestion and inadvertent disclosure. Finally, routine quality improvement requires standardized, locally valid measurement: developing and validating Ugandan, language-appropriate patient-reported experience measures and embedding them in facility monitoring. These steps can produce actionable evidence to redesign services, strengthen trust, improve retention, and advance equitable outcomes.

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