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Clients' Perspectives on Switching from Old Stable ART Regimens to New Dolutegravir-based Regimen at Joint Clinical Research Centre Uganda

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Abstract

In 2018, Uganda adopted Dolutegravir (DTG)-based regimens as the preferred first-line antiretroviral therapy (ART). This qualitative study explored the perspectives of people living with HIV (PLHIV) regarding switching from stable ART regimens to DTG at the Joint Clinical Research Centre (JCRC). We purposively sampled 24 participants (16 DTG-experienced, 8 DTG-naïve) and conducted face-to-face in-depth interviews. Data were analysed using inductive thematic analysis. DTG-experienced participants were those switched to DTG from a previous stable regimen, while DTG-naïve participants were eligible for but had not yet switched. Key themes emerged: (1) Initial apprehension due to fear of side effects, feeling stable on previous regimens, and perceiving the switch as compulsory or rushed; (2) Appreciation for DTG's benefits (e.g., smaller pill size, once-daily dosing, rapid viral suppression) which mitigated initial hesitancy over time; (3) The critical role of communication and preparation in facilitating a positive transition experience. The findings indicate that while switching from stable treatment initially creates tension, hesitancy decreases as benefits are realized and concerns are addressed through continuous,

supportive health education. Effective client-provider communication is essential for successful ART policy transitions.

Keywords: Antiretroviral Therapy, Dolutegravir, HIV, Treatment Switch, Qualitative Research, Uganda, Patient Perspectives

Introduction

Globally, an estimated 39.9 million people were living with HIV in 2024, with approximately 70% residing in sub-Saharan Africa(1). Antiretroviral therapy (ART) has transformed HIV into a manageable chronic condition, significantly reducing morbidity and mortality and improving the quality of life for people living with HIV (PLHIV) (2). By the end of 2023, 30.7 million PLHIV were receiving ART, a substantial increase from 7.7 million in 2010, though still below global targets (1).

In 2018, the World Health Organization (WHO) recommended Dolutegravir (DTG)-based regimens as the preferred first- and second-line ART due to their efficacy, high genetic barrier to resistance, favorable side-effect profile, and dosing convenience (3). Uganda adopted this guidance, rolling out the Tenofovir/lamivudine/Dolutegravir (TLD) fixed-dose combination nationally (4, 5). DTG offers advantages over previous regimens like Efavirenz (EFV), including faster viral suppression and reduced long-term toxicities (6, 7). However, its rollout raised concerns about potential side effects such as weight gain, neuropsychiatric symptoms, and initially, neural tube defects in infants born to women on DTG at conception (8-10).

While studies have examined clinical outcomes and healthcare provider perspectives on DTG (11, 12), there is a paucity of in-depth qualitative research exploring the experiences and perspectives of PLHIV themselves, particularly those asked to switch from a regimen on which they were clinically stable. Understanding these perspectives is crucial for patient-centered care, improving adherence, and ensuring the success of national treatment policy changes. This study therefore aimed to explore the perspectives of PLHIV at the Joint Clinical Research Centre (JCRC) in Uganda regarding the switch from a stable ART regimen to a DTG-based therapy.

Methods

Study Setting

The study was conducted at the Joint Clinical Research Centre (JCRC) in Lubowa, Kampala. JCRC is a leading HIV treatment and research centre in Uganda. Since 2018, JCRC has implemented the Ministry of Health guidelines by switching virologically suppressed PLHIV from first- and second-line ART to DTG-based regimens. The centre serves a large population of PLHIV from across Uganda, making it an appropriate setting for this inquiry.

Study Design and Philosophical Approach

We employed a qualitative study design using narrative inquiry (13). This approach was chosen to elicit rich, detailed stories from participants about their personal experiences with the ART switch, allowing us to understand the meaning they ascribed to this transition within the context of their lives. However, to ensure a systematic analysis of patterns across narratives, we utilized inductive thematic analysis for data analysis (14). This combination allowed us to capture individual depth while identifying common themes across the participant group.

Researcher Characteristics and Reflexivity

The research team consisted of public health specialists and clinicians with extensive experience in HIV care and qualitative research in Uganda.

The first author (FK), a Master of Public Health student at Makerere University at the time of data collection (August-October 2022), conducted all interviews. At that time, FK was not affiliated with JCRC and had no clinical role at the facility. FK has since joined JCRC in a research capacity, but this affiliation began after data collection was completed.

This temporal separation ensured that participants perceived FK as independent of their clinical care team during interviews.

The second author (KKK) was affiliated with JCRC throughout the study period, including during data collection, analysis, and manuscript preparation. KKK's role at JCRC was in research and data management, not

direct clinical care of participants. To minimize potential bias arising from his institutional affiliation, KKK was not involved in participant recruitment or interviews. His contributions were focused on providing methodological guidance, supporting data analysis (conducted independently with FK), and contributing to manuscript revisions. Regular team debriefings included discussions about how our institutional affiliations might influence interpretation, and all authors collectively reviewed findings to ensure balanced reporting.

The co-authors (JKB, SN, JBMD) are affiliated with Makerere University School of Public

Health and Busitema University, and were not employed by JCRC during the study period.

Their external perspectives provided additional checks against institutional bias.

To enhance reflexivity, the research team maintained regular debriefing sessions throughout data collection and analysis. In these sessions, we discussed how our professional backgrounds, institutional affiliations, and assumptions might influence data interpretation. We consciously bracketed our clinical and institutional knowledge to remain open to participants' lived experiences. Field notes were maintained to document initial impressions and potential biases.

Participants' Selection and Sampling

We used purposive sampling with maximum variation to capture a diverse range of experiences (15). The sampling frame was drawn from the Integrated Clinical Enterprise Application (ICEA) patient database. Eligibility criteria included: being aged 18 years or older, living with HIV, and for the DTG-experienced group, having been on a stable (virally suppressed) non-DTG ART regimen for at least one year before switching to DTG. The DTG-naïve group comprised eligible clients (virally suppressed on a non-DTG regimen) who had not yet been switched.

From an initial pool of 200 eligible clients, 50 (36 DTG-experienced, 14 DTG-naïve) were purposively selected by a data manager to ensure diversity in age, sex, and treatment history. These potential participants were contacted by telephone. Twenty-four consented to participate (16 DTG-experienced, 8 DTG-naïve). The final sample was structured to include variation in sex, age group (18-35 vs. >35 years), and for the DTG-experienced group, duration on DTG (≤ 6 vs. > 6 months) (Table 1). Reasons for non-participation among the 26 contacted who declined included lack of time, disinterest, or not being reachable. No further recruitment efforts were made beyond the initial contact, as data saturation (the point where no new substantive themes emerged) (16) was achieved with the 24 interviews.

Group	Sub-category	Male	Female	Total
DTG-experienced	Duration: ≤ 6 months	4	4	8
	Age: 18-35 years	(2)	(2)	
	Age: >35 years	(2)	(2)	
	Duration:>6 months	4	4	8
	Age: 18-35 years	(2)	(2)	
	Age: >35 years	(2)	(2)	
Total DTG-exp.		8	8	16
DTG-naïve	N/A	4	4	
	Age: 18-35 years	(2)	(2)	
	Age: >35 years	(2)	(2)	

Total	DTG-	4	4	8
naïve				
Overall Total		12	12	24

Table 1. Participant sampling framework

Data Collection

Two research assistants (a nurse and a data manager) with prior experience in qualitative research and proficiency in both English and Luganda were recruited to support data collection logistics. Their roles included identifying potential participants from the clinic database, making initial telephone contact to explain the study, and scheduling interview appointments. They were not involved in the clinical care of the participants to minimize bias. The first author (FK) conducted all interviews. At the time of interview, FK was introduced as a researcher from Makerere University, not as a healthcare provider, to reduce social desirability bias. Participants were informed that the interviewer was independent of their clinical care team. Separate semi-structured interview guides were developed for DTG-experienced and DTG-naïve participants (Supplementary File 1). The guides were designed to elicit narratives around the switch experience, covering: knowledge, feelings, and experiences at the time of switch; perceived risks and benefits; treatment observations; and adherence.

The guides were pre-tested with two PLHIV (one DTG-experienced, one naïve) at a different health facility to assess clarity, flow, and duration, and were subsequently refined. They were initially developed in English, translated to Luganda by a certified translator, and then back-translated to English to ensure conceptual equivalence (17). Participants chose their preferred interview language (English or Luganda).

Twenty-four in-depth interviews were conducted face-to-face in private rooms at JCRC between August and October 2022. Each interview lasted 45-60 minutes, was audio-recorded with consent, and supplemented with brief field notes. Data collection ceased upon reaching thematic saturation, confirmed

through team discussions after batches of interviews were transcribed and reviewed (16). Transcripts were not returned to participants for comment due to logistical constraints, but member checking was approximated through ongoing probing during interviews to confirm understanding.

Data Analysis

Audio recordings were transcribed verbatim and translated into English where necessary. Transcripts were checked for accuracy against the recordings. We followed Braun and Clarke's six-phase framework for inductive thematic analysis (14): 1) Familiarization with data; 2) Generating initial codes; 3) Searching for themes; 4) Reviewing themes; 5) Defining and naming themes; 6) Producing the report. Data were managed using NVivo 12 software.

Coding was conducted independently by two researchers (FK and KKK), who then met to compare, discuss, and reconcile codes to enhance reliability. Themes were derived inductively from the data, not from a pre-existing framework. Rigor was ensured through team debriefings, maintaining an audit trail, and using verbatim quotes to support findings (18). Socio-demographic data were analyzed descriptively. Socio-demographic data were analyzed descriptively. Rigor was enhanced through independent coding, team debriefings, and adherence to COREQ reporting guidelines (Supplementary File 2).

Ethical Considerations

Ethical approval was granted by the Makerere University School of Public Health Higher Degrees Research and Ethics Committee (MakSPH-HDREC-032). Administrative permission was obtained from JCRC. All participants provided written informed consent. They were informed of their right to withdraw at any time without affecting their care. All data were anonymized, stored on password-protected computers, and handled confidentially. The study adhered to the principles of the Declaration of Helsinki.

Results

Participants' characteristics

We interviewed 24 participants (12 women, 12 men) aged 20 to 59 years. Most had been living with HIV for over ten years and had experienced multiple ART regimen switches prior to the potential DTG switch. All participants had formal education. Thirteen described themselves as married or cohabiting. DTG-experienced participants had been on their pre-switch regimen for 1.7 to 12 years and on DTG for 3 to 40 months. Five DTG-experienced participants self-reported suboptimal adherence post-switch. Detailed characteristics are in Table 2.

ID	Age (Years)	Sex	Marital status ^a	Education	Years Since HIV Diagnosis	Years on ART pre-switch
DTG-experienced						
01	20-30	Female	Single	Post-Secondary	10-15	5-10
02	50-60	Female	Separated	Secondary	10-15	5-10
03	20-30	Male	Married/Cohabiting	Secondary	1-5	1-5
04	40-50	Male	Married/Cohabiting	Secondary	1-5	1-5
05	40-50	Male	Separated	Secondary	10-15	5-10
06	20-30	Female	Single	Post-secondary	1-5	1-5
07	20-30	Male	Married/Cohabiting	Post-secondary	1-5	1-5
08	50-60	Female	Separated	Post-secondary	10-15	10-15
09	20-30	Female	Married/Cohabiting	Post-secondary	5-10	5-10
10	20-30	Female	Single	Secondary	10-15	5-10
11	50-60	Female	Widowed	Secondary	1-5	1-5
12	20-30	Male	Married/Cohabiting	Secondary	1-5	1-5

13	40-50	Male	Married/Cohabiting	Post-secondary	1-5	1-5
14	50-60	Female	Married/Cohabiting	Secondary	10-15	10-15
15	40-50	Male	Married/Cohabiting	Post-secondary	10-15	5-10
16	20-30	Male	Single	Secondary	1-5	1-5
DTG-naïve						
17	20-30	Male	Married/Cohabiting	Post-secondary	10-15	N/A
18	50-60	Female	Married/Cohabiting	Primary	15-20	N/A
19	20-30	Male	Single	Secondary	1-5	N/A
20	30-40	Female	Married/Cohabiting	Post-secondary	10-15	N/A
21	30-40	Male	Married/Cohabiting	Secondary	10-15	N/A
22	20-30	Female	Married/Cohabiting	Secondary	10-15	N/A
23	20-30	Male	Single	Primary	10-15	N/A
24	50-60	Female	Widowed	Post-secondary	15-20	N/A

Table 2. Characteristics of participants (n=24).

^aMarriage/Cohabiting (couples sharing a home, intimacy, economic resources, and, in some cases, raising children together)

^bOptimal adherence (took drugs daily on time); suboptimal adherence (Failed to take drugs daily and or on time)

Themes

Analysis yielded three overarching themes, each with sub-themes, capturing the perspectives of both DTG-experienced and DTG-naïve participants.

Theme 1: Apprehension and Perceived Coercion in the Face of Change

This theme captures the initial emotional and cognitive responses of participants when confronted with the prospect of switching from a familiar, stable ART regimen to a new one. Across both groups, participants described a period of heightened anxiety and uncertainty. This apprehension was not merely a passive worry but an active state of

questioning, information-seeking, and in some cases, resistance. The narratives revealed that this fear was rooted in three interconnected experiences: the dread of unknown or observed side effects, the psychological comfort derived from long-term stability on their previous regimen, and a feeling that the switch was imposed upon them without adequate consultation or choice. These elements combined to create a perception of the switch as a potentially threatening event rather than a neutral or beneficial clinical update.

- **Fear of Side Effects:** This was the most prominent concern across both groups. Participants, especially those over 35 with long treatment histories, dreaded side effects like weight gain, diabetes, and insomnia, often based on rumors or observing others. The fear was visceral and personal, as illustrated by one participant's account: *"I feared... because I read that it can worsen diabetes. So, that also made me fear to be switched."* (DTG-naïve, female, 57). Another described witnessing side effects in peers: *"Before my switch I saw some people who had been switched, with side effects of leg swelling, failure to sleep and some reported reduced functionality in bed. That is why I was hesitant."* (DTG-experienced, male, 42).
- **Perceived Compulsoriness of the Switch:** Many DTG-experienced participants felt they had no choice in the matter, describing the switch as a directive rather than a shared decision. This perception of coercion eroded their sense of agency. *"I was told it was a government policy... I had no decision to make. Because I wanted to follow instructions."* (DTG-experienced, male, 47). Another echoed: *"When it is a policy, you don't have a choice... you just accept whether you have been hurt or not."* (DTG-experienced, male, 50).
- **Feeling rushed and Under-informed:** Some felt the switch happened abruptly without adequate preparation or time for questions. This rushed experience left them feeling disoriented and distrustful. *"I was surprised... I thought I was going to be given my*

usual drug, only to be told... I was to take the new medication." (DTG-experienced, female, 34). Another described actively postponing the switch multiple times due to feeling unprepared: *"I prolonged the counsellor. She could tell me we want to switch you today, I say am not ready first wait... fourth time she had to send me to the Doctor."* (DTG-experienced, male, 30).

Theme 2: Navigating the Transition: From Disruption to Adjustment

This theme describes the dynamic process participants underwent after the switch was implemented. It was not a static experience but a journey characterized by initial disruption, followed by various coping mechanisms, and culminating for many in a gradual acceptance of the new regimen. The data show that participants actively worked to make sense of the change, sometimes reframing it positively to regain a sense of control. While the transition was challenging, particularly due to disruptions in long-established routines, the emergence of tangible benefits-both practical and clinical-played a crucial role in shifting perspectives from reluctance to appreciation. This theme highlights the resilience of participants and the factors that facilitated their adaptation.

- **Disruption of Stability and Routine:** Several DTG-experienced participants missed their old regimen, feeling it was working well. Changing dosing times (e.g., from night to morning) was particularly disruptive to daily life and adherence. *"I used to take the old ART at 9pm, yet this new medicine was to be taken in the morning... It was very disturbing for me to swallow in the morning... sometimes I would miss the morning dose."* (DTG-experienced, female, 28). Another expressed regret: *"I did not have the issues am having at the moment. I have taken DTG for 3 years... I was really doing well with my previous medication."* (DTG-experienced, male, 43).

- **Re-interpreting the Switch as a Reward:** Some participants reframed the switch positively, viewing it as a reward for good adherence rather than an arbitrary policy imposition. This cognitive reframing appeared to restore a sense of pride and validation. *"They recommended my file because I qualified... my viral load was very low."* (DTG-experienced, female, 33). This interpretation transformed the switch from a threat into an acknowledgment of their health management success.
- **Gradual Acceptance through Experiencing Benefits:** Over time, many DTG-experienced participants came to appreciate DTG's practical advantages, which also appealed to DTG-naïve participants. This acceptance was not immediate but evolved as participants experienced or anticipated the benefits first hand.
 1. **Appreciation of Simplified Treatment:** The smaller pill size and once-daily dosing were universally praised as life-changing improvements. *"The entire pill burden! Here you take one pill per day yet before we used to take like four pills in the morning and evening. The other thing, it is easy to swallow."* (DTG-experienced, female, 59).
 2. **Trust in Clinical Efficacy:** Belief in DTG's superior viral suppression motivated acceptance despite lingering fears. Participants balanced their concerns against the promise of better health outcomes. *"The viral load suppression... is very good because many people were not adhering and had high viral loads. Now days people have done well after being switched to DTG."* (DTG-naïve, female, 40).

Theme 3: The Centrality of Communication and Preparedness

This overarching theme emerged not merely as one finding among many, but as the fundamental lens through which all other experiences were filtered. Participants consistently emphasized that the quality, timing, and nature of information and support from healthcare providers was the single most

important factor shaping their entire switch experience—from initial fear to eventual acceptance. When communication was perceived as inadequate, technical, or delivered in a top-down manner, it amplified anxiety and reinforced feelings of coercion. Conversely, participants expressed a clear vision of what effective communication would look like: proactive, empathetic, and dialogic. This theme underscores that in the absence of high-quality communication, even a clinically superior medication can become a source of distress.

- **Critique of Inadequate Communication:** A common narrative was that explanations were insufficient, overly technical, or delivered in a rushed manner, leaving participants with unanswered questions and heightened anxiety. *"They didn't explain to me much. They just told me that they are going to change me because am taking well."* (DTG-experienced, female, 33). This lack of depth in communication was directly linked to the fear and uncertainty described in Theme 1.
- **Desire for Proactive, Reassuring Dialogue:** Participants expressed a need for earlier, clearer, and more empathetic conversations that addressed their specific fears and allowed for questions. They wanted to be treated as partners in care, not passive recipients of policy. The absence of such dialogue was keenly felt. The ideal was articulated not in abstract terms but as a contrast to their actual experience: a conversation where their stability on the old regimen was acknowledged, their fears were taken seriously, and the rationale for change was collaboratively explored.

Discussion

This study provides nuanced insights into the perspectives of PLHIV navigating a policy-mandated switch to DTG in Uganda. The findings reveal a complex emotional and cognitive journey marked by initial apprehension but moving towards gradual acceptance, heavily influenced by the quality of client-provider communication.

Our finding that fear of side effects was a primary barrier aligns with studies on ART initiation and switches elsewhere (19, 20). However, it contrasts with research from Spain and the US where strong pre-existing patient-provider relationships mitigated such fears (21).

This underscores the contextual nature of treatment transitions and highlights that in settings like Uganda, where consultation times may be limited, fears based on community narratives can significantly impact perceptions. The perception of the switch as compulsory or rushed resonates with concerns about "policy-led" care potentially undermining patient autonomy, as noted in studies from Zambia (22). This perception can foster passive acceptance rather than informed partnership, which is crucial for long-term adherence (23).

The positive reframing of the switch as a "reward" for good adherence and the high value placed on DTG's practical benefits (reduced pill burden, dosing simplicity) are critical findings. These factors served as powerful motivators that helped overcome initial hesitancy, supporting evidence that treatment convenience enhances adherence (24). This suggests that while clinical superiority drives policy, from the patient perspective, practical superiority may be equally salient in driving acceptance.

The overarching theme underscoring all others is the fundamental role of communication. Participants' experiences-whether of fear, coercion, or reassurance-were directly linked to how the switch was communicated. This finding powerfully aligns with and extends the literature on patient-centered care in chronic disease management (25). It suggests that the success of a national ART policy change depends not just on the drug's clinical profile, but on the implementation strategy at the clinic level. Effective strategies must move beyond informational leaflets to include proactive, iterative, and empathetic dialogue that acknowledges patient fears, validates their stability on previous regimens, and collaboratively builds a rationale for the change.

Strengths and Limitations

A key strength is the in-depth exploration of perspectives from both those who had switched and those awaiting the switch, providing a comprehensive view. The use of narrative inquiry captured rich, contextual data. Rigor was enhanced through independent coding, team debriefings, and adherence to COREQ reporting guidelines (Supplementary File 2).

Limitations include the single-site, cross-sectional design, which limits generalizability and our ability to track perspective changes longitudinally. Participants were all from a research-focused clinic, and their experiences may differ from those in public or private clinics. Social desirability bias may have led to under-reporting of negative views, though efforts were made to minimize this by using interviewers independent of clinical care. Transcripts were not returned to participants for comment, which may have limited member checking. Future research should employ longitudinal designs across diverse settings and include healthcare provider perspectives to triangulate findings.

Conclusions and Recommendations

This study demonstrates that switching clinically stable PLHIV to a new ART regimen, even a superior one, is not merely a clinical decision but a significant psychosocial transition. Initial apprehension is common and rooted in fear of side effects, attachment to stability, and perceptions of coercion. However, this hesitancy can be effectively mitigated by the tangible benefits of the new regimen and, most importantly, by high-quality, patient-centered communication.

We recommend that:

1. **National and facility-level switch protocols** should mandate and allow time for dedicated, pre-switch counselling sessions that use clear, non-technical language to explain reasons, benefits, and potential side effects, while actively inviting and addressing patient concerns.

2. **Healthcare worker training** should emphasize communication skills for managing patient transitions, focusing on shared decision-making and empathy to replace perceptions of coercion with partnership.
3. **Peer support programs** could be leveraged, where early adopters of DTG share positive experiences, to address community-level rumors and fears.
4. **Future research** should evaluate the effectiveness of different communication interventions in improving patient experiences and adherence outcomes during ART switches.

By centering patient perspectives and improving communication, programs can ensure that the clinical promise of DTG is fully realized through supportive and respectful implementation.

Additional Files

Supplementary File 1: Interview Guides (DTG-experienced and DTG-naïve).

Supplementary File 2: COREQ (Consolidated Criteria for Reporting Qualitative Research) Checklist

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Author contributions

FK and JKBM conceptualized and designed the study. FK led data collection, including conducting all interviews, with supervision from KKK. Two research assistants supported participant recruitment and scheduling. FK and KKK independently coded and analyzed the data, with regular debriefing and input from JKBM, SN, and JBMD. KKK provided methodological guidance and supported data analysis while maintaining awareness of his institutional affiliation to minimize bias. FK drafted the initial manuscript. JKBM, KKK, SN, and JBMD provided critical revisions and contributed to the interpretation of findings.

All authors reviewed and approved the final version of the manuscript.

Data availability statement

The data that support the findings of this study are not openly available due to reasons of sensitivity and are available from the corresponding author upon reasonable request. fkanyike@jcrc.org.ug.

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Declarations

Competing interests

The authors declare no competing interests.

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