



Research Article

Exploring Reasons For Starting Antiretroviral Treatment Early Among Patients In South Africa

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ABSTRACT

All people living with HIV (PLHIV), regardless of CD4 count or clinical stage, are eligible for immediate initiation of antiretroviral therapy (ART) under the Universal Test and Treat (UTT) approach. Although a high proportion of individuals have been tested, diagnosed, and initiated on ART, retention in HIV care remains a significant challenge. An exploratory qualitative study design was employed among PLHIV enrolled in the UTT programme in the Ekurhuleni District, located east of Johannesburg in Gauteng Province, South Africa. In-depth interviews were conducted with 26 PLHIV aged 18 years and older who had initiated ART and had been on treatment for at least 6–12 months. All interviews were audio-recorded, transcribed verbatim, managed using NVivo version 12 software, and analysed thematically. Five major themes emerged regarding reasons for early ART initiation: (1) fears and doubts about starting ART, (2) motivation to initiate ART early, (3) anticipated benefits of early ART initiation, (4) perceptions of ART in comparison to basic needs and other treatments, and (5) perceptions regarding discontinuation of ART. The finding found that public awareness, continuous counselling and support for PLHIV are needed to increase UTT uptake and retain those already in HIV care.

Keywords: Benefits of starting ART, Fear, Motivation, Public Awareness

INTRODUCTION

The HIV/AIDS epidemic continues to be one of the world's most significant public health challenges, having claimed nearly 33 million lives to date. By the end of 2019, an estimated 38.0 million people were living with HIV globally; of these, 25.4 million had access to antiretroviral therapy (ART). During the same period, approximately 1.7 million individuals were newly infected with HIV, and about 690,000 people died from AIDS-related illnesses worldwide (UNAIDS, 2020). Furthermore, data from the Joint United Nations Programme on HIV/AIDS (UNAIDS) indicated that in Eastern and Southern Africa, 20.7 million people were living with HIV, 730,000 new HIV infections occurred, and approximately 300,000 deaths were attributed to AIDS-related illnesses by the end of 2019.



The rollout of free antiretroviral (ARV) drugs in the South African public health sector has evolved progressively since 2004 (Simelela & Venter, 2014) and has now been in operation for more than 15 years. Currently, ARV drugs are widely accessible and provided free of charge at all primary health care (PHC) facilities and public hospitals across South Africa. When the programme was first implemented in 2004, eligibility for ART was limited to HIV-positive individuals with a CD4 cell count below 200 cells per cubic millimetre and those classified as having World Health Organization (WHO) clinical stage 4 disease. Five years later, the WHO revised its treatment guidelines for developing countries, recommending ART initiation for individuals with a CD4 cell count below 350 cells per cubic millimetre or WHO clinical stage 3. As a developing country, South Africa adopted these guidelines and implemented them until the end of 2012, when further revisions were introduced. In 2013, South Africa adopted updated WHO recommendations, expanding ART eligibility to include all HIV-positive individuals with a CD4 cell count below 500 cells per cubic millimetre, all HIV-infected pregnant women, individuals in HIV-discordant relationships, and patients with active tuberculosis or hepatitis B infection, regardless of CD4 cell count (Simelela & Venter, 2014).

Following the introduction of the Universal Test and Treat (UTT) programme in South Africa, a high proportion of people living with HIV (PLHIV) have been diagnosed and initiated on ART. However, retaining at least 90% of those initiated on lifelong treatment remains a significant challenge. Koole et al. (2014) reported that retention in ART care continues to be a major concern across sub-Saharan Africa. Evidence from the literature indicates that approximately one in four individuals initiated on ART through the UTT programme is lost to follow-up within the first year (Shabalala et al., 2018). Data from the District Health Information System (DHIS) further show that in the Ekurhuleni Health District, retention at 12 months among ART-naïve adult clients initiated between April 2017 and March 2018 was only 61.7%, with an average loss to follow-up rate of 38.3%.

Despite the widespread availability of HIV treatment and expanded eligibility for ART initiation, some PLHIV remain hesitant to start or continue treatment, particularly when they are asymptomatic at the time of diagnosis (Horter et al., 2019). Conversely, Olivia et al. (2016) found that individuals who had accepted their HIV-positive status were more likely to recognise the need for treatment compared with those who remained in denial. Studies conducted in sub-Saharan Africa among clients initiated on ART under the UTT programme have shown that perceptions of illness and wellness strongly influence decisions to initiate and remain on treatment (Nhassengo et al., 2018; Shabalala et al., 2018). Additionally, Horter et al. (2017) reported that PLHIV on ART often perceive daily treatment adherence as a personal responsibility.

In South Africa, HIV/AIDS remains a major public health challenge due to persistently high infection rates and the urgent need for effective intervention strategies. Although there is broad consensus that early initiation of ART and sustained adherence are critical for achieving optimal treatment outcomes, limited evidence exists on the specific motivations influencing individuals' decisions to initiate ART early and remain on treatment over time. To address this gap, the present study aims to explore the complex motivations and challenges experienced by South African patients in initiating and maintaining ART. By examining the factors that shape decision-making processes and contribute to favourable long-term treatment outcomes, this study seeks to inform the development of targeted interventions and strategies that address the unique socio-cultural, psychological, and systemic determinants of early ART initiation and adherence in the South African context.

MATERIAL AND METHODS

This study employed an exploratory qualitative design and was conducted among people living with HIV (PLHIV) who had initiated antiretroviral therapy (ART) under the Universal Test and Treat (UTT) programme in the Ekurhuleni North sub-district. Ekurhuleni District is located east of Johannesburg in Gauteng Province, South Africa, and is administratively divided into three sub-districts: South, East, and North. The North sub-district comprises 26 primary health care (PHC) facilities and two community health care (CHC) centres. Services provided at the CHC centres include HIV/AIDS management, tuberculosis (TB) services, reproductive health, maternity care, integrated management of childhood illnesses, the Expanded Programme on Immunisation, mental health services, non-communicable disease management, youth-friendly services, as well as curative and emergency care. PHC facilities operate on weekdays from 08:00 to 16:30, with some facilities opening on Saturdays from 08:00 to 14:00, while CHC centres operate 24 hours a day. With regard to HIV/AIDS services, all facilities provide free care and support to PLHIV in accordance with guidelines from the National Department of Health and the World Health Organization (WHO). An electronic patient management system (Tier.Net) is used to capture and manage data for all patients receiving ART. This system supports the monitoring of ART patients and the generation of consolidated data on key HIV indicators. ART patients are primarily managed by lay counsellors who provide adherence counselling and by nurses trained in Nurse Initiation and Management of Antiretroviral Therapy (NIMART), who are responsible for clinical and medical management.



Figure 1: The map of City of Ekurhuleni

The study population comprised male and female adults aged 18 years and older who were living with HIV, had been initiated on ART under the UTT programme, had been on treatment for at least 6–12 months, and were actively accessing HIV services at health facilities in the Ekurhuleni North sub-district.

Participant recruitment commenced after ethical clearance was obtained from the Sefako Makgatho Health Sciences University Research Ethics Committee (SMUREC), as well as permission from the Gauteng Provincial Department of Health, the Ekurhuleni Research Ethics Committee, and the managers of the selected health facilities. Prior to data collection, the study was introduced to key healthcare workers (HCWs), including queue marshals, clerks, data capturers, lay counsellors, and nurses at each facility. This process facilitated the development of an effective

recruitment strategy, as the study objectives and eligibility criteria were clearly explained to all involved HCWs.

Health facilities were notified one day in advance of the planned data collection. On the day of data collection, HCWs played a key role in identifying potential study participants by generating a list of eligible PLHIV scheduled for routine clinic appointments, using the electronic patient register. These lists were securely stored in a locked drawer in the facility's data room and retrieved on the day of data collection. The lists were then taken to the reception area, where patients register for their clinical files. At the point of registration, HCWs privately informed eligible individuals about the study within the service delivery area. Potential participants who expressed interest were referred to the researcher or research assistant, who provided detailed information about the study and invited them to participate in an interview. Following each interview, participants were assisted by HCWs to access their clinical services promptly in order to minimise any delays to their care.

Purposive sampling was employed to select participants for this study, as it enabled the researcher to obtain rich, in-depth information from a specifically defined group, thereby enhancing the relevance and precision of the findings. A heterogeneous sample of PLHIV including both men and women aged 18 years and older who had initiated ART through the UTT programme and had been on treatment for 6–12 months was intentionally selected. The 6–12-month period on ART was considered sufficient for participants to have gained meaningful experiences and insights regarding ART initiation and adherence. A total of 26 PLHIV on ART were interviewed, with selection guided by age and duration since ART initiation.

Data were collected through individual in-depth interviews conducted by the researcher and a trained research assistant. Interviews were conducted in participants' preferred languages (English, isiZulu, or Sesotho). Given the sensitive nature of the research topic, individual interviews were deemed appropriate to protect participants' confidentiality, including their identity and HIV status. A semi-structured interview guide developed by the researcher, comprising open-ended questions and a demographic section, was used to facilitate data collection. Prior to the interviews, the researcher provided participants with a clear explanation of the study, including its title, aim, and objectives. Participants were informed that participation was voluntary and that they had the right to withdraw from the study at any time without any consequences. Only participants who provided written informed consent were interviewed.

Demographic data forms were completed by the researcher before the interviews were conducted by the research assistant. All interviews were audio-recorded with participants' consent and conducted in private consultation rooms at the health facilities to ensure confidentiality. Each interview lasted approximately 20–35 minutes. At the end of each day of data collection, the researcher and the research assistant held debriefing sessions to reflect on the interviews and identify emerging issues for further exploration. Data collection continued until data saturation was achieved.

The research assistant who supported the data collection process holds a master's degree in research psychology and has over 20 years of experience participating in various research projects. Prior to and during the data collection period, the research assistant received additional orientation on the study objectives, ethical guidelines, and the specific data collection techniques employed.

A total of 26 individual in-depth interviews were conducted with PLHIV who had initiated ART under the UTT programme between 30 June 2021 and 30 September 2021. The interviews were conducted by the researcher and the research assistant using a semi-structured interview guide developed by the researcher. The questions were not asked in a fixed chronological order; rather,

the sequence was guided by participants' responses to allow for flexibility and depth in data exploration. Open-ended questions were used to elicit participants' personal experiences of initiating and taking ART, followed by probing questions to encourage participants to elaborate on issues that may not have been explicitly covered in the interview guide. All interviews were audio-recorded with participants' consent, transcribed verbatim, and securely stored on a password-protected laptop. The data were also backed up on an external hard drive to prevent data loss.

Participant and researcher safety ensured by implementing safety measure. The safety measure including minimise the risk of SARS-CoV-2 transmission during the data collection process.

- The researcher and research assistant conducted daily self-screening for COVID-19 symptoms prior to fieldwork. If either reported any symptoms, interviews were rescheduled to a later date.
- Interview rooms were well ventilated and arranged to maintain the recommended physical distancing of at least 1.5 metres.
- A maximum of four participants were interviewed per day to limit potential exposure at the research site.
- Each participant underwent COVID-19 symptom screening before the interview to assess their risk of infection.
- Tables and chairs used during interviews were disinfected between participants.
- Hand sanitisation was performed by the researcher, research assistant, and participants both before and after each interview.
- Wearing a face mask was mandatory for participation, and all participants complied with this requirement.
- A COVID-19 contact-tracing register was developed and maintained to facilitate retrospective contact tracing if required.

All audio-recorded interviews were transcribed verbatim into Microsoft Word documents, and transcripts conducted in local languages were translated into English. To ensure accuracy, the researcher repeatedly listened to the audio recordings while reading the transcripts. All transcripts were carefully reviewed and validated before analysis. Emerging themes and sub-themes were identified through an iterative reading process and were discussed with the supervisor to confirm their relevance and alignment with the study objectives. The final set of 26 English-language transcripts was uploaded into NVivo version 12 qualitative data analysis software for systematic coding and analysis. The outputs of the data analysis including themes, sub-themes, and verbatim excerpts from the interview transcripts were used to present and support the study findings.

Ethical clearance for the study was obtained from the School of Health Sciences Research Ethics Committee and the Sefako Makgatho Health Sciences University Research Ethics Committee (SMUREC/H/179/2020:PG). Following ethical approval, permission to conduct the study was secured from the National Health Research Database and the Ekurhuleni Health District Research Ethics Committee (GP_202012_022). Additional approval to collect data was obtained from the managers of the selected primary health care (PHC) facilities.

RESULTS

The majority of participants were middle-aged, with ages ranging from 18 to 72 years. Approximately two-thirds of the participants were female (62%). Half of the participants were unmarried, while 27% were married and 23% were cohabiting. In terms of educational attainment, 42% had completed secondary education, followed by those with matriculation certificates (31%). Participants with primary education and those who were unable to read or write each accounted for 12%, while only a small proportion had tertiary education (3%). More than half of the participants were employed (58%), 38% were unemployed, and 4% were still attending school.

With regard to antiretroviral therapy (ART) initiation, the majority of participants (85%) reported initiating treatment on the same day they were diagnosed with HIV, while the remaining 15% commenced ART within 14 days of diagnosis. Analysis of the interview data revealed five major themes related to reasons for early initiation of ART. These themes were: (1) fears and doubts about starting ART, (2) motivation to initiate ART early, (3) anticipated benefits of early ART initiation, (4) perceptions of ART in comparison to basic needs and other treatments, and (5) perceptions regarding discontinuation of ART (Table 1).

Table 1: Themes and sub-themes

Themes	Sub-themes
Perceptions of starting ART early by PLHIV	Fears and doubts about starting ART Motivation to start ART early Anticipated benefits of starting ART Comparing ART to basic needs and other treatments Perceptions about stopping ART

Fears and doubts about starting ART

Misinformation and rumours were reported to generate fear and doubt, which in turn discouraged some people living with HIV/AIDS from initiating treatment. Participants described several fears and uncertainties that they experienced prior to starting antiretroviral therapy (ART). These concerns are illustrated in the following excerpts:

“I had the fear, and I was scared to test because already the person I was dating, was sick (already had HIV). I was afraid, not knowing where to start and how am I going to deal with this because I heard people saying when you start taking treatment you will have bad dreams and also that you develop breasts like a woman that made me more afraid but there was nothing, I can do but to test” (P4, 34-year-old male, 12 months on ART).

“I thought because I had a problem with the pain in my heart and I thought maybe when I drink them, they will change my body shape maybe my complexion will change I was just scared of that” and, “I thought I would be darker; I was scared because I didn’t know how they would treat me” (P22, 30-year-old female, 10 months on ART).

Motivation to start ART early

In accordance with the Universal Test and Treat (UTT) programme, all individuals newly diagnosed with HIV are offered the opportunity to initiate ART immediately following diagnosis. Participants in this study described various reasons that motivated them to start ART soon after diagnosis. These motivations included self-determination and acceptance of their HIV status without assigning blame, awareness of the risks associated with living with HIV without treatment, understanding of the progressive nature of the disease, personal observations, dreams, and a strong desire to live, recover, and maintain their health. The following excerpts illustrate these motivations:

“I decided to drink them as I wanted to live, I wanted to achieve a lot of things, why must I stop myself from that.... so, I started drinking them” (P26, 18-year-old female, 6 months on ART).

“Because I want to live, I want to fulfil my dreams, there is a lot that I want to do in life” (P3, 37-year-old female, 12 months on ART).

Anticipated benefits of starting ART

Though some of the participants reported that they had fears and doubts about starting ART early, others expected to benefit from the UTT programme.

“The most important one is that I can’t even infect anyone that’s the advice that I got, I’m not a danger to anyone anymore unlike the time when I was not taking it. If I’m not taking medication, I’m a danger to other people but if I’m taking medication, I know everyone is safe around me in terms of contracting HIV” (P19, 46-year-old male, 12 months on ART).

“What I know is that when I drink them, I am reducing the chances of me dying quickly” (P22, 30-year-old female, 10 months on ART).

“I feel good because this is an opportunity for me to live longer” (P1, 29-year-old male, 9 months on ART).

Perceptions about stopping ART

Stopping ART can result in dire health outcomes. Being sick, danger to other people and death were mentioned as some of the consequences that may result in stopping ART. This is what the participants said:

“I will be stressing people who will be looking after me when I’m sick” (P12, 41-year-old male, 12 months on ART).

“If I’m not taking medication, I’m a danger to other people but if I’m taking medication, I know everyone is safe around me in terms of contracting HIV” (P19, 46-year-old male, 12 months on ART).

“I know if I stop taking them, which means it is the end of me” (P25, 48-year-old male, 12 months on ART).

Adherence and compliance with ART

Adherence to ART is essential for effective viral suppression and for strengthening the immune system, thereby maintaining overall health and wellbeing. Poor adherence to ART is associated with suboptimal viral load suppression, which not only compromises patients’ immediate health outcomes but also increases the risk of developing long-term drug resistance. Most participants in this study reported that they adhered strictly to their treatment instructions. However, some acknowledged occasional missed doses due to forgetfulness or competing daily activities. Participants noted that when a dose was missed, they took the medication as soon as they remembered. The following excerpts illustrate participants’ experiences with ART adherence:

“I never skipped a day or forget taking treatment, I might be late in taking it by maybe 2 or 3 minutes, but I never skipped a day” (P1, 29-year-old male, 9 months on ART).

“I remember I skipped one day because I could not get that tablet, so I took it the following day” (P17, 42-year-old female, 7 months on ART).

“I have never missed or forgotten to take them; I just miss the time” (P3, 37-year-old female, 12 on ART).

DISCUSSION

Given that this study targeted people living with HIV (PLHIV) who had already initiated antiretroviral therapy (ART), most participants reported being relatively healthy at the time of diagnosis, with only a few having experienced significant illness prior to ART initiation. This provided an opportunity to explore motivations for early ART initiation among both participants who were asymptomatic and those who were unwell at diagnosis. Participants who were not ill prior to HIV diagnosis reported having preconceived perceptions about initiating ART early, largely driven by fears and doubts regarding potential side effects. Commonly cited concerns included fears of developing psychosis, breast enlargement in men, changes in skin tone, and experiencing disturbing dreams.

Despite these fears and uncertainties, participants expressed optimism about initiating ART early. Those who presented at healthcare facilities while feeling unwell reported a strong desire to start treatment immediately in order to regain their health, feel better, and prolong their lives. Similarly, participants who were asymptomatic indicated that their motivation for early ART initiation was to maintain good health and prevent future illness. These findings are supported by Boyd et al. (2019), who reported that ART prolongs life expectancy and enables PLHIV to regain strength and maintain good health. In addition, similar findings have been reported in previous studies by Kim et al. (2016) and Horter et al. (2017), which demonstrated that decisions to initiate HIV treatment were influenced by healthcare workers' advice, encouragement from significant others, fear of disease progression, and the desire to remain healthy. Furthermore, a study conducted by Chadambuka et al. (2018) among pregnant women in Zimbabwe found that willingness to initiate ART was strongly linked to the desire to feel better and live a normal life.

Beyond personal health benefits, some participants recognised the broader preventive advantages of early ART initiation. One participant noted that adherence to treatment not only improves personal health outcomes but also prevents HIV transmission to others, emphasising that achieving an undetectable viral load renders the virus untransmittable. This finding aligns with the World Health Organization's (2016) recommendation for early ART initiation and is supported by Rodger et al. (2016), who demonstrated that ART significantly reduces the risk of HIV transmission between sexual partners. Early ART initiation is central to achieving the UNAIDS 90–90–90 targets, as early diagnosis, prompt treatment initiation, and sustained adherence lead to faster viral suppression and reduced onward transmission (Boyd et al., 2019). This is particularly relevant for HIV-positive pregnant women, as viral suppression enables safe breastfeeding without the risk of transmitting HIV to infants (Chadambuka et al., 2018).

Participants' perceptions of HIV treatment played a crucial role in facilitating adherence. ART was not viewed as a burden but rather as a necessary and beneficial component of daily life. Many participants described HIV as comparable to other chronic conditions that require lifelong medication, reinforcing the normalisation of ART within their daily routines. This finding is consistent with a study conducted in Addis Ababa, Ethiopia, which reported a decline in HIV-related stigma as increasing numbers of individuals began to perceive HIV as a manageable chronic condition due to improved access to healthcare services (Dessaiegn et al., 2019). A similar trend is evident in South Africa, where the implementation of the Universal Test and Treat (UTT) programme has made ART universally accessible to all individuals diagnosed with HIV.

Despite acknowledging the benefits of early ART initiation, participants strongly believed that discontinuing treatment was not an option. Many equated stopping ART with a “death wish,” expressing concern that discontinuation would lead to deterioration of their health and a return to the physical state that initially prompted them to seek care. Participants emphasised their desire to live longer, support their families, preserve their dignity, and protect others from infection. The perceived dangers of living with HIV without treatment and the risk of disease progression were powerful motivators for initiating ART immediately and adhering consistently. ART was widely regarded as a life-saving intervention that restores dignity, prevents onward transmission, and enables PLHIV to achieve a life expectancy comparable to that of HIV-negative individuals. These findings are consistent with Agustin et al. (2018), who similarly reported that participants viewed discontinuation of ART as unacceptable due to the perceived life-threatening consequences.

Limitations of the study

This study has several limitations. First, the sample comprised only people living with HIV (PLHIV) who had initiated antiretroviral therapy (ART) under the Universal Test and Treat (UTT) programme and who had remained in care for a period of 6–12 months. As such, the findings may not fully capture the experiences of individuals who delayed ART initiation or who were lost to follow-up. Second, given the sensitive nature of the research topic, some participants became emotional during the interviews, which may have led to incomplete recall or the omission of certain experiences.

Participants’ responses may also have been influenced by their familiarity with healthcare workers involved in recruitment and by the clinic-based setting in which the interviews were conducted, potentially introducing social desirability bias. Finally, data collection took place during the COVID-19 pandemic, and adherence to infection prevention measures—such as physical distancing and the use of face masks—negatively affected the audio quality of some recordings. This resulted in additional time required for transcription and translation.

Recommendation

Based on the study findings, the following recommendations are proposed to strengthen HIV testing uptake, promote early initiation of antiretroviral therapy (ART), and improve retention in care among people living with HIV (PLHIV) in the era of Universal Test and Treat (UTT).

- **Public health awareness** - Since the implementation of the UTT programme in 2016, South Africa has made substantial progress in the fight against HIV. A growing proportion of individuals are aware of their HIV status, HIV-related mortality has declined due to early ART initiation, and viral suppression among PLHIV on ART has significantly reduced onward transmission. These benefits of the UTT programme should be consistently communicated and reinforced, not only among healthcare workers but also to the general public. Public awareness campaigns should utilise multiple platforms—including community outreach, mass media, and digital channels—to address persistent myths, reduce stigma, and encourage timely HIV testing and treatment initiation.
- **Continuous counselling** - Unlike previous treatment models, where PLHIV underwent multiple counselling sessions before ART initiation, the UTT approach often results in rapid treatment initiation with limited ongoing psychosocial support. This may leave some individuals inadequately prepared to cope with an HIV diagnosis, lifelong treatment, potential side effects, disclosure challenges, and related psychosocial stressors, increasing

the risk of treatment default. Continuous counselling should therefore be integrated into HIV care beyond diagnosis and ART initiation. Ongoing counselling services can help address emotional, psychological, and social challenges, thereby promoting sustained adherence to ART and long-term retention in care.

Social support - Social support for PLIV is enabling them to sustained ART adherence and retention in care for PLHIV. Support mechanisms should be strengthened and maintained for all individuals on ART, regardless of their clinical status. Health facilities should revive and strengthen PLHIV support groups and actively encourage participation in peer-support networks. Such platforms provide opportunities for shared experiences, emotional support, and practical guidance, which can enhance resilience, reduce isolation, and support long-term engagement in HIV care.

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CONFLICT OF INTEREST

None declared.

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