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Research Article

Living with HIV at the Point of Antiretroviral Therapy Initiation: A Qualitative Study of Health-related Quality of Life and Readiness for Treatment at a Tertiary Hospital in South Africa

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ABSTRACT

Background: In the era of expanded antiretroviral therapy (ART), global HIV targets increasingly emphasise health-related quality of life (HRQoL) as a "fourth 95", yet there is limited in-depth, patient-centred evidence on how adults in resource-constrained settings experience HRQoL and readiness to start ART.

Aims: This study explored how people living with HIV in a South African public sector clinic perceive their quality of life across key HRQoL domains and how these perceptions shape readiness to initiate or adhere to ART.

Methods: A descriptive qualitative study using in-depth, semi-structured interviews was conducted with 11 adults living with HIV who were newly diagnosed and initiated on ART. Interviews explored physical health, emotional and psychological responses, independence and daily functioning, social relationships and stigma, environmental and structural conditions, and spirituality and desired healthcare support. Audio recordings were transcribed verbatim and analysed using reflexive thematic analysis.

Results: Participants' HRQoL perceptions directly influenced ART readiness and anticipated adherence, with experiences of stigma, mental health burden, transport barriers and economic insecurity sometimes undermining confidence in starting and sustaining treatment. Findings generated from participants' lived experiences highlighted multidimensional HRQoL across physical, psychological, independence, social, environmental and spiritual domains. Participants described highly heterogeneous baseline quality of life, ranging from "brilliant" and unchanged daily functioning to profound illness, fatigue and recurrent hospitalisation. Emotional responses included shock, sadness, fear of job loss and suicidal feelings, but also acceptance and positive reframing, often supported by peer groups and faith. Social experiences ranged from supportive partners, families and community groups to severe rejection, isolation and homelessness. Environmental and structural barriers, including transport, clinic distance, unsafe housing and unemployment, were central concerns that patients linked directly to self-care, nutrition and treatment continuity. Spirituality and religious practice were prominent coping resources, though views on integrating faith into formal care were mixed. Across domains, stigma, economic insecurity and health system constraints emerged as cross-cutting influences on HRQoL and ART readiness. Participants' HRQoL perceptions directly influenced ART readiness and anticipated adherence, with experiences of stigma, mental health burden, transport barriers and economic insecurity sometimes undermining confidence in starting and sustaining treatment.

Conclusion: Improving HRQoL and supporting ART initiation in this setting will require integrated approaches that address stigma, social and economic vulnerability, mental health and spiritual needs alongside biomedical management, positioning quality of life as a core outcome of HIV care.

Keywords: *People living with HIV; Antiretroviral therapy; Health-related quality of life; Spirituality; Barriers to care.*

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1. Introduction

The widespread availability and effectiveness of combination antiretroviral therapy (ART) have substantially improved survival for people living with HIV (PLHIV), contributing to a shift toward HIV as a manageable chronic condition and, for many, near-normal life expectancy (Iheagwara et al., 2025). Consequently, HIV care has increasingly moved beyond biomedical indicators such as viral suppression and CD4 restoration to include broader outcomes reflecting how individuals live with HIV over time (Safreed-Harmon et al., 2019). Expert guidance now argues that "therapeutic success" should incorporate quality of life (QoL) alongside traditional efficacy and safety endpoints (Antela et al., 2021). Health systems similarly recognise health-related quality of life (HRQoL) as an essential complement to viral suppression in long-term HIV management (Lazarus et al., 2021).

Despite treatment advances, PLHIV continues to experience persistent physical symptoms (e.g., fatigue, pain), psychological distress (e.g., depression, anxiety), and social challenges such as stigma and discrimination, all of which can undermine HRQoL even in high-ART-coverage settings (Vu et al., 2020). QoL is typically defined using the World Health Organization's framework as individuals' perceptions of their position in life within their cultural and value systems and relative to their goals and expectations (WHOQOL Group, 1995). HRQoL is conceptualised as a multidimensional construct encompassing physical, psychological, social, and environmental domains (Sosnowski et al., 2010).

This multidimensionality is particularly relevant in HIV care, where health outcomes are shaped not only by clinical status and treatment effects but also by stigma, disclosure concerns, and structural determinants that influence daily functioning and access to care (Degroote, Vogelaers & Vandijck, 2014). Empirical evidence demonstrates considerable heterogeneity in HRQoL across populations, reflecting variation in clinical stability, adherence, comorbidities, and ageing (Mohammed et al., 2021; Hyle et al., 2024; Desta et al., 2020; Portilla-Tamarit, 2024). Increasingly, psychosocial and environmental factors are recognised as equally influential to, or more influential than, clinical variables among ART-treated populations (Xu et al., 2017). Assessing HRQoL at ART initiation is critical because patients' lived perceptions of health, stigma, economic security, and support strongly influence treatment readiness and subsequent adherence, and thus the likelihood of achieving durable viral suppression and long-term wellbeing. Yet, in South African public-sector HIV services, qualitative studies that directly connect patients' HRQoL perceptions to ART readiness and early adherence decisions remain scarce.

Assessing HRQoL at ART initiation is critical because patients' lived perceptions of health, stigma, economic security, and support strongly influence treatment readiness and subsequent adherence, and thus the likelihood of achieving durable viral suppression and long-term wellbeing. However, several gaps remain in the literature. First, most HRQoL studies in HIV have been quantitative and focused on patients already on ART, with limited in-depth qualitative evidence from the point of diagnosis and treatment initiation. Second, existing qualitative work in sub-Saharan Africa has often examined stigma, mental health or adherence separately, rather than explicitly linking multidimensional HRQoL perceptions to readiness to start and sustain ART. Third, there is limited context-specific evidence from South African public-sector services on how adults interpret and prioritise different HRQoL domains when deciding whether to begin treatment. Yet, in South African public-sector HIV services, qualitative studies that directly connect patients' HRQoL perceptions to ART readiness and early adherence decisions remain scarce. Within this context, the present study provides an in-depth qualitative exploration of how adults living with HIV in a South African public-sector setting perceive their quality of life across key HRQoL domains, physical, psychological, independence, social, environmental, and spiritual and how these perceptions influence readiness to initiate ART. By focusing on individuals at ART initiation in a resource-constrained setting, the study contributes to a nuanced understanding of HRQoL and informs efforts to operationalise the "fourth 95" in similar contexts.

2. Methods

Study Design

A descriptive, qualitative, cross-sectional design was employed to explore perceptions of HRQoL and ART readiness among adults living with HIV at diagnosis or treatment initiation. A qualitative descriptive approach was

appropriate because the study aimed to capture participants' lived experiences of HRQoL and ART readiness in a way that stayed close to their own words and everyday meanings, rather than imposing a complex theoretical framework. This study was situated within an interpretivist paradigm, which assumes that reality is socially constructed and that participants' perceptions of HRQoL and ART readiness are best understood through their subjective meanings, lived experiences, and social contexts. This approach enabled in-depth exploration of lived experiences and meanings that are not readily captured by quantitative measures.

Setting

The study was conducted at a tertiary public-sector hospital in South Africa serving a predominantly low-income urban–rural population.

Participants and Sampling

Participants were recruited from the HIV/ART service at the tertiary public-sector hospital where the study was conducted. Potential participants were identified during routine clinic attendance if they were newly diagnosed with HIV or were about to initiate ART and were approached in person in the clinic by the researcher after referral or indication from clinic staff that they met the broad study criteria. The purpose of the study was explained, and those interested were screened for eligibility and invited to participate voluntarily in a private setting. Inclusion criteria were age 18 years or older, confirmed HIV-positive status, and being newly diagnosed, pre-ART, or in the early ART initiation phase. Patients who were acutely unwell, unable to provide informed consent, or too distressed to participate in an interview were excluded. Purposive sampling was chosen because the study sought information-rich cases from individuals with direct, recent experience of HIV diagnosis and ART initiation, and because this strategy is well-suited to qualitative research aiming for depth, diversity of perspectives, and conceptual relevance rather than statistical representativeness. Sampling continued until thematic saturation was reached (11 participants). Therefore, the final sample comprised 11 PLHIV, including 4 women and 7 men, aged between 27 and 55 years.

Data Collection

All interviews were conducted by a health professional who was not involved in the direct clinical care of participants and had no prior therapeutic relationship with them. The interviewer was experienced in qualitative research methods and trained on the study protocol and interview guide, a design choice intended to minimise social desirability bias and encourage open discussion of sensitive experiences. Semi-structured, in-person interviews were conducted in private clinical settings using a semi-structured interview guide informed by the WHOQOL domains and the existing literature. The guide was designed to explore participants' lived experiences of HIV diagnosis, quality of life and readiness to start ART across physical, emotional, independence, social, environmental and spiritual domains. Core questions asked how participants described their current health and quality of life, how they felt after diagnosis, whether HIV had affected work, daily tasks or independence, and how relationships, disclosure and stigma were experienced. Additional questions explored housing, transport and financial constraints, as well as faith and spiritual coping. ART readiness was probed explicitly by asking how participants felt about starting ART, what they expected from the medication, what might make adherence difficult, and what support or information they felt they needed to take consistently. Interviews were audio-recorded and supplemented with field notes. Flexible probing allowed participants to elaborate on their experiences.

Data Preparation and Analysis

Audio-recorded interviews were transcribed verbatim, anonymised and read repeatedly to support immersion in participants' narratives. An interpretivist, reflexive thematic analysis approach was used, following Braun and Clarke's six-phase framework of familiarisation, coding, theme development, review, definition and reporting. Initial coding was inductive: the corresponding researcher systematically worked through each transcript, assigning descriptive and interpretive codes to segments of text that captured participants' experiences of physical health,

emotions, independence, relationships, living conditions, spirituality and ART readiness. Codes were then collated into provisional clusters by examining conceptual similarities and tensions across interviews, and these clusters were developed into candidate themes that described patterned meanings in how adults living with HIV perceived HRQoL and treatment readiness.

Themes were iteratively refined by rereading transcripts and ensuring that each theme was internally coherent, distinct from other themes, and grounded in multiple participants' accounts. Subthemes were created where needed to capture important nuances within broader themes (for example, differentiating shock and fear from acceptance and positive reframing within emotional responses). The coding framework and emerging themes were discussed within the research team to support reflexive consideration of assumptions and alternative interpretations, and to ensure that themes remained closely linked to the data rather than to preconceived ideas. Although one researcher led the primary coding, theme development and writing, interpretations were reviewed collaboratively, and verbatim quotations from different participants were used within the manuscript to illustrate each theme and demonstrate the range of perspectives represented.

Trustworthiness was enhanced through credibility (prolonged engagement with the data and use of verbatim quotations), dependability (maintaining an audit trail of key methodological decisions), confirmability (researcher reflexivity and team discussion of emerging interpretations), and transferability (thick description of the study setting and participant characteristics.

During analysis, the team discussed how their positions as health professionals and researchers could influence which issues were foregrounded, and consciously sought to represent both distress and resilience, as well as supportive and rejecting social responses, rather than privileging any single narrative. These reflexive strategies helped to manage potential bias and ensure that themes remained grounded in participants' lived accounts rather than in pre-existing clinical or theoretical frameworks.

Ethical Considerations

Ethical approval was obtained (M230239 MED 23-1-094). Participants provided written informed consent, and confidentiality was maintained through anonymisation and secure data storage.

3. Results

The analysis of 11 in-depth interviews generated a rich, multidimensional picture of how adults living with HIV perceived their quality of life and readiness to initiate ART. Reflexive thematic analysis yielded six overarching HRQoL domains: physical health (symptoms, energy, functional capacity), psychological wellbeing (emotional responses, coping, hope), independence (ability to manage daily tasks, work, self-care and decisions), social relationships (disclosure, stigma, support, isolation), environmental conditions (housing, transport, clinic access, economic resources) and spirituality (faith, religious practice, meaning-making.

HRQoL and Readiness to Initiate ART

Across the interviews, participants' experiences of HRQoL appeared to influence their readiness to initiate ART in different ways. Participants who perceived themselves as physically stable and able to maintain their usual routines generally viewed treatment as manageable. For example, one participant stated, *"I don't think it will really disturb any of my routine and my daily work routine. I will be fine"* (Participant 1). Similarly, another participant expressed confidence in treatment by saying, *"Nothing yet has changed… I don't think it will affect anything as long as I just stick to my regimen"* (Participant 6). Some participants were explicitly ready to begin treatment, with one stating, *"We are ready to start the medication as soon as possible"* (Participant 7). These accounts suggest that preserved physical functioning, acceptance of the diagnosis and confidence in maintaining daily routines facilitated ART readiness.

However, readiness was more uncertain among participants experiencing physical symptoms, emotional distress or socioeconomic difficulties. One participant described being in pain, feeling increasingly ill and being *"always in hospital time and again"* (Participant 2), while another reported sadness and fear of losing employment (Participant 4). These experiences potentially made ART seem more difficult to initiate and sustain. Concerns about

stigma and disclosure also affected confidence in treatment. One participant explained, *"I'm losing my freedom, because… I fear who will know my personal (HIV) status"* (Participant 2). Thus, although treatment was recognised as necessary, concerns about stigma, emotional well-being, and the ability to preserve work, privacy and independence complicated readiness to begin ART.

Social and structural circumstances further shaped participants' perceptions of whether ART could be incorporated into everyday life. Support from partners and community groups appeared to strengthen readiness; for example, one participant reported that their partner would provide support and that community and support groups were available (Participant 7). In contrast, other participants described isolation, homelessness, unemployment, food insecurity and difficulty accessing transport or distant clinics. These accounts indicate that ART readiness was determined not only by participants' knowledge of treatment or clinical condition but also by whether they felt socially supported and had the practical resources to attend the clinic and continue treatment.

Perceived Quality of Life and Physical Health

Baseline quality of life

Patients described baseline quality of life at diagnosis as ranging from positive to impaired. Several, particularly those already on treatment or recently diagnosed, characterised their well-being as *"Brilliant"* (Patients 3, 5, 8), suggesting that HIV had not yet disrupted daily functioning. Others linked diagnosis to ongoing illness, reporting *"Not very good, very sick"* (Patient 4) or *"Okay… I have been very sick and tired, and I blamed it on my asthma"* (Patient 1), indicating that HIV was experienced within a broader pattern of sickness and diminished health. These accounts suggest that perceptions of QoL were shaped not only by HIV status itself but also by how participants interpreted their symptoms and prior health experiences.

Physical symptoms and functional capacity

Physical health experiences also varied. Many patients reported minimal impact, stating *"I accept it. No, I experience nothing"* (Patients 3, 5) and *"nothing yet has changed… I don't think it will affect anything as long as I just stick to my regimen"* (Patient 6). These accounts frame HIV as currently asymptomatic and suggest confidence in treatment preserving function. In contrast, one participant described a substantial burden: *"Yes, I'm having pain. I'm sicker, you see? And… I'm always in hospital time and again"* (Patient 2), linking pain and recurrent admission to poorer QoL. Such variation underscores the uneven ways in which HIV is experienced at diagnosis, with some already feeling physically affected while others remain largely asymptomatic.

Expectations and concerns about ART side-effects

Expectations of ART were mostly optimistic. Several patients said, *"I don't expect any impact on my treatment"* (Patient 8) and *"it doesn't really seem that it will give me any physical challenges"* (Patient 6). Others described routine adherence: *"how to drink tablets. No, nothing, nothing has changed"* (Patients 3, 5). Still, some acknowledged possible concerns, including *"Side effects of medication, sticking to medication… Nothing much worries me"* (Patient 7), showing awareness of adherence demands. Overall, participants viewed ART as necessary and manageable, with side effects acknowledged but not strongly foregrounded in their accounts. Perceptions of physical health influenced readiness in two ways: participants who felt well or asymptomatic generally viewed ART as manageable and were more confident about starting and adhering to treatment, whereas those experiencing pain, fatigue or repeated hospitalisation expressed greater concern about whether treatment demands would be easy to sustain.

Emotional and Psychological Response

Initial shock, sadness and fear

Diagnosis often triggered shock and sadness. One participant said, *"It was a shock, and I was sad as expected, but I am keeping my emotions high and the stress low"* (Patient 6). Others reported persistent sadness, *"Lately… I just feel very sad"* (Patient 1) and fear related to work security: *"Very sad and fear of losing job"* (Patient 4). These responses show that emotional reactions were closely tied to both the meaning of the diagnosis and its perceived social consequences.

Ongoing stress, suicidal ideation and future anxiety

For some, distress persisted. One participant described *"Suicide feeling… I attend support group"* (Patient 10), while another reported *"Sometimes, I get confused mentally… I feel like I'm losing my mentality"* (Patient 2). Future concerns were also clear: *"I want to have children one day… that is what's keeping me stressed"* (Patient 1). These narratives indicate that HIV was not only understood as a health condition, but also as something that threatened future identity, family formation and psychological stability.

Coping, acceptance and positive mindset

Many participants emphasised coping through acceptance. One stated, *"I'm still the same person… I still have confidence in myself. I still have a future"* (Patient 3), while another said, *"No mood changes… It's fine… I just take it the way it is"* (Patient 7). A present-focused approach was also evident: *"Every day, I only take it one day at a time. I hope this will be ok"* (Patient 2). This suggests that resilience and positive framing were important ways of managing uncertainty and sustaining hope. Emotional responses strongly shaped readiness, with acceptance, hope and positive reframing supporting willingness to initiate ART, while shock, sadness, fear, confusion and suicidal thoughts created hesitation and heightened concern about coping with lifelong treatment.

Independence, Daily Functioning and Role Performance

Capacity to manage daily tasks and work

Most patients said HIV had not compromised daily functioning. They emphasised continuity: *"I'm still… the person I was before… I'm still doing the same thing I used to do… able to go to collect my medication on time"* (Patients 3, 5), and *"I don't think it will really disturb any of my routine and my daily work routine. I will be fine"* (Patient 1). Another noted, *"It didn't affect anything"* (Patient 9). These accounts suggest that when symptoms were minimal, everyday responsibilities could still be maintained.

Maintaining productivity, self-care and routines

Some reported no change: *"No, I'm self-sufficient… No change"* (Patients 5, 8) and *"Everything should still steadily go right"* (Patient 6). Others linked HIV to hardship: *"I'm not working. I can't eat healthy…"* (Patient 2), showing how socioeconomic vulnerability can undermine self-care, nutrition and productivity. The findings suggest that maintaining routine depends not only on health status but also on social and economic stability. Where participants felt able to maintain routines, self-care and productivity, they were more likely to view ART as something they could integrate into daily life; by contrast, perceived loss of independence and disrupted functioning reduced confidence in their ability to sustain adherence.

Social Relationships, Stigma and Support

Disclosure patterns and selective openness

Disclosure was cautious and selective. Some had not told anyone: *"I have not disclosed to anybody as yet, as I'm still dealing with this by myself"* (Patient 6) and *"As I just found out, I haven't told anybody else yet"* (Patient 1). Others told only partners or trusted people: *"So only the partner will know about your status… partner is going to support"* (Patient 7) and *"my partner and friends"* (Patient 9). These patterns show how anticipated stigma shapes disclosure decisions.

Experiences of isolation and rejection

Some participants described rejection and isolation: *"My family, friends, they have isolated me… Not even one person visited me"* (Patient 2) and *"all my family and friends left me single"* (Patient 10). One also reported homelessness: *"chased… out of my house. I started staying in the street now"* (Patient 2). Such accounts show that HIV-related stigma could extend into practical loss of shelter and social protection.

Supportive relationships and community groups

In contrast, others reported strong support: *"everyone supported"* (Patient 8) and *"don't have any challenges"*

(Patients 3, 5). Community structures mattered too: *"Yes, community group and support group"* (Patient 7) and *"community core group helps… Adherence groups help"* (Patient 8). These sources of support appeared to buffer stigma and promote continued engagement in care.

Social relationships influenced readiness by shaping participants' expectations of encouragement or rejection after diagnosis. Supportive partners, family members and community groups appeared to strengthen motivation and confidence in adherence, whereas stigma, isolation and fear of disclosure undermined readiness and made treatment seem harder to manage.

Environmental and Structural Constraints

Housing, neighbourhood safety and transport

Some participants said their environment would not affect care, while others faced major barriers such as *"Clinic is very far, struggling with job and transport"* (Patient 9) and *"chased… out of my house. I started staying in the street now"* (Patient 2). These barriers show how place and living conditions shape access to ART and the ability to remain consistent with treatment.

Economic insecurity and employment

Financial strain was a major concern. One participant said, *"It affected me because I'm not working. I can't eat healthy…"* (Patient 2). Others named *"Transport, money, job"* (Patient 9) and *"I want money, unemployed"* (Patient 10), showing how economic insecurity shaped treatment readiness and everyday well-being. Environmental and structural conditions directly affected readiness by shaping participants' perceptions of the treatment's practical sustainability. Stable access to transport, housing and food supported confidence in adherence, whereas poverty, distance to care and homelessness contributed to fear that ART could not be maintained consistently.

Spirituality, Meaning-Making and Healthcare Support

Spiritual beliefs and church attendance

Spirituality was an important coping resource. Participants described themselves as *"Very religious, go to church every week"* (Patient 10) and *"Normally I'm gonna go to church"* (Patient 7). Faith was said to *"help morally"* (Patient 4) and support renewed effort: *"I'm willing to give another chance and do better this time"* (Patient 2).

Integration of faith-based support into care

Views on faith in care were mixed. Some said *"Yes"* (Patients 2, 4, 9, 10), while others preferred separation: *"No, they shouldn't. They shouldn't really be incorporated"* (Patient 6). Another said faith would be part of daily life: *"On a day-to-day basis, like I normally [practice]"* (Patient 8). This suggests the need for flexible, patient-centred approaches.

Information, reassurance and continuity of care

Participants wanted more support from health professionals, including *"More help from doctors, more information"* (Patient 4) and reassurance that *"everything will be fine, and I can live a normal life"* (Patient 6). They also asked for *"The advice. Some advice… counselling, advice, and hope"* (Patients 3, 5, 8) and *"with no bias or no stigma, that I can just ask and be answered and be helped"* (Patient 1).

Spiritual beliefs and supportive healthcare relationships often enhanced readiness by fostering hope, meaning and emotional reassurance, although preferences differed regarding how faith should be incorporated into care. Clear information, non-judgmental counselling and reassurance from healthcare professionals helped participants feel more prepared to begin and continue ART.

4. Discussion

A central contribution of this study is the finding that HRQoL perceptions did not merely describe how participants were living with HIV; they actively shaped treatment readiness at the point of ART initiation. Participants who perceived themselves as physically stable, emotionally able to cope, socially supported and practically able to

attend care were generally more ready and motivated to start ART and more confident that adherence would be manageable (Okonji, Wyk & Mukumbang, 2022; Golin et al., 2016). In contrast, participants whose quality of life was marked by pain, emotional distress, fear of disclosure, social rejection, unstable housing, transport difficulties, or unemployment often described ART through the lens of burden and uncertainty, suggesting reduced readiness or concern about sustaining adherence over time (Mgbere et al., 2018; Quinn et al., 2018; Holtzman, Brady & Yehia, 2015). In this way, HRQoL served as a real-time appraisal of whether treatment was feasible, meaningful, and compatible with everyday life, rather than as a separate outcome to be considered only after ART had begun.

Participants' accounts of severe rejection, isolation and relationship breakdown are consistent with evidence that HIV related stigma is linked to social disconnection, diminished support and poorer wellbeing among PLHIV (Fekete, Williams & Skinta, 2018; Hutton, Misajon & Collins, 2013). Qualitative studies document relational consequences such as withdrawal and losses in informal networks when stigma is anticipated or enacted, echoing narratives of being "chased out" or left "single" after diagnosis (Koku, 2024; Poku et al., 2023). Associations between stigma, loneliness and reduced social integration are also observed in older PLHIV, where both experienced and internalised stigma relate to loneliness and lower social support, indicating that interpersonal isolation can co-occur with measurable health-relevant outcomes (Pollak, 2025; De Main, 2025).

The mixed responses in our data, for example, supportive partners but rejecting friends, align with disclosure research showing distinct "classes" associated with higher social support, while stigma and disclosure concerns continue to shape which ties remain safe (Nuwahereza et al., 2026; Nkulu-Kalengayi, Ouma & Hurtig, 2026). Evidence suggests that strengthening relationship quality and dyadic coping may help mitigate the impacts of stigma within romantic partnerships (Rzeszutek et al., 2026), while broader, strong support is associated with flourishing and quality of life and can attenuate stigma-linked internalisation processes (Brown et al., 2023). At the same time, some contexts exhibit complex or paradoxical stigma–support patterns, underscoring the need to assess the type, source, and reliability of support rather than assuming uniform protection (Zhang & Zhang, 2025).

Participants' reports of transport / and clinic distance mirror evidence that PLHIV may avoid local services and seek care elsewhere to manage stigma and privacy concerns. Anticipated stigma prompted care seeking at remote facilities and care avoidance, adding travel burdens and practical access constraints to stigma (Wanjala et al., 2023). Similarly, internalised stigma was associated with avoiding the local clinic when needed, indicating that "place-based" access is shaped by both service geography and perceived social risk (Tran et al., 2022). Our findings on economic insecurity, unemployment, inability to eat healthily, and worries about "transport, money, job" are consistent with HIV studies identifying income and related structural disadvantage as determinants of treatment experience, with non-adherence associated with low income and education alongside self-stigma and limited socio-familial support (Dzramado, Oduro & Lasim, 2026).

Participants' initial shock and sadness after diagnosis resonate with qualitative evidence where diagnosis was described as overwhelming and linked to fear, distress, secrecy and isolation (Owusu, 2022). Ongoing distress and cognitive strain in our sample showed persistent mental health needs that impede engagement, with unmet depression and anxiety needs identified as barriers across the care continuum (Poku et al., 2023a). Similarly, participants described food insecurity and intimate partner violence co-occurring with poor mental health and substance use in self-reinforcing cycles, illustrating how structural hardship and psychological distress compound one another (Tenkorang & Owusu, 2026). Future-oriented anxiety in our study parallels post-diagnosis concerns that often centre on anticipated health decline and navigating treatment, with distress sometimes predating testing (Obeagu & Alsadi, 2025). In contrast, narratives of acceptance and positive reframing taking life "one day at a time," maintaining confidence in the future, align with evidence that peer support and strategic coping foster hope, non-judgmental acceptance, and resilience amid structural adversity (Karugaba et al., 2023).

Participants' strong religious practice and descriptions of spirituality as a source of moral and motivational support are consistent with HIV qualitative literature showing that faith can function as a meaning-making resource that supports emotional regulation and a "living positively" orientation. In studies conducted with PLWHV, "accepting one's faith" has been described alongside self-care, disclosure, and participation in support groups as a coping strategy that sustains emotional equilibrium after diagnosis-related shock and despair (Obeagu & Alsadi, 2025; Poku et al., 2023b). Broader psychosocial syntheses similarly emphasise that PLHIV commonly experiences fear, uncertainty, grief and stigma, and that attending to spiritual needs and fostering positive

thinking/faith are frequently positioned as part of comprehensive psychosocial support (Zahra et al., 2024). However, spirituality may have mixed implications for care. Evidence indicates that PLHIV use spiritual practices to cope with depression, yet some prefer spiritual healing over professional care, with depression affecting self-care and ART adherence, suggesting potential risks when spirituality substitutes for clinical and psychosocial services rather than complementing them (Lattanner & Azia et al., 2023). This mixed pattern supports integrating spiritually sensitive counselling and referral pathways that preserve beneficial faith-based coping while avoiding delays in mental health and HIV care.

These findings reinforce the argument that HRQoL assessment at the point of ART initiation is not merely descriptive, but central to identifying psychosocial and structural barriers to readiness and adherence, enabling clinicians and programme managers to intervene early to support sustained engagement in care.

Implications of the Study Findings

These findings have important implications for patient-centred HIV care, specifically at the time of ART initiation. Because participants' readiness was shaped by how they perceived their physical health, emotional coping, social support, living conditions, and beliefs, ART initiation should routinely include a structured yet conversational assessment of HRQoL domains, rather than focusing solely on clinical eligibility and regimen choice. Clinicians and counsellors could use early encounters to explore patients' fears, treatment expectations, experiences of stigma, transport and housing constraints, and spiritual resources, and then tailor information, counselling, and adherence planning to these lived realities. In practice, this means integrating brief mental health screening and referral pathways, actively involving social workers or lay counsellors to address economic and transport barriers, and inviting discussion of faith and spirituality in ways that support coping while reinforcing the importance of continued ART. Such patient-centred approaches at initiation may increase not only immediate willingness to start ART but also the perceived feasibility of sustaining adherence over time, thereby advancing both viral suppression and the "fourth 95" goal of good HRQoL for PLHIV.

Recommendations

Routine assessment of HRQoL should be incorporated into HIV care before ART initiation to identify patients who may need additional emotional, social or practical support to start and sustain treatment. HIV services should also integrate psychosocial care, mental health screening and referral, stigma-reduction strategies, and social support interventions, including help with transport, food insecurity, housing instability and counselling, to strengthen ART readiness and adherence. In addition, future longitudinal qualitative studies are needed to examine how HRQoL perceptions, coping, and treatment readiness change over time after ART initiation and how these changes influence long-term adherence and wellbeing.

Strengths & Limitations

A key strength of this study is that it explores HRQoL and ART readiness in depth, moving beyond biomedical outcomes to capture the lived realities of adults living with HIV. The qualitative design allowed participants to describe their physical, psychological, social, environmental, and spiritual experiences in their own words, yielding rich, context-specific insights. The use of semi-structured interviews provided both consistency and flexibility, while data collection continued until thematic saturation was reached, thereby strengthening credibility. In addition, the study used a rigorous analytic approach and trustworthiness strategies that support the dependability and confirmability of the findings.

This study has a few limitations. First, it was conducted at a single public-sector hospital with only 11 participants, so the findings may not be generalised to other settings or populations. Second, participants were adults at ART initiation or early treatment; the study captures experiences at one point in the HIV care continuum and may not reflect longer-term changes over time. Finally, the use of self-reported interviews may also have introduced recall or social desirability bias, and interpretation of the data was shaped by the researcher's perspective despite efforts to ensure trustworthiness.

5. Conclusion

This study shows that HRQoL perceptions directly shape readiness to initiate and maintain ART. Participants who perceived themselves as emotionally able to cope, socially supported and practically able to manage treatment were more ready and motivated to start ART and more confident about sustaining adherence, whereas distress, stigma, unstable housing, transport barriers and economic insecurity made ART seem harder to begin and maintain. These findings show that HRQoL is not only an outcome of HIV care but also an important determinant of treatment readiness at the point of initiation. Assessing HRQoL before ART initiation should therefore form part of routine HIV care, as it can help identify patients who need additional psychosocial, mental health or practical support to start treatment successfully and remain engaged in care over time.

Conflict of Interest

The authors declare no conflict of interest.

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References

Alhassan, A., Offei, F. O., Ofori, G. O., Nabe, B., Gunu, A. I., Craymah, J. P., Nortey, A. N., Doe, P. F., Asiedu, C., & Amoadu, M. (2026). A scoping review of barriers and facilitators of antiretroviral therapy adherence in Sub-Saharan Africa, 2000-2024. *Discover Public Health, 23*(1), 1126. https://doi.org/10.1186/s12982-026-02255-9

Antela, A., Rivero, A., Llibre, J. M., & Moreno, S. (2021). Redefining therapeutic success in HIV patients: An expert view. *Journal of Antimicrobial Chemotherapy, 76*(10), 2501-2518. https://doi.org/10.1093/jac/dkab168

Brashers, D. E., Neidig, J. L., & Goldsmith, D. J. (2004). Social support and the management of uncertainty for people living with HIV or AIDS. *Health Communication, 16*(3), 305-331. https://doi.org/10.1207/S15327027HC1603_3

Brown, M. J., Gao, C., Kaur, A., Qiao, S., & Li, X. (2023). Social support, internalized HIV stigma, resilience and depression among people living with HIV: A moderated mediation analysis. *AIDS and Behavior, 27*(4), 1106-1115. https://doi.org/10.1007/s10461-022-03847-7

De Main, A. S., Glesby, M. J., Johnston, C., Brennan-Ing, M., & Siegler, E. L. (2025). Patterns of social engagement and associations with depression, loneliness and stigma in people living with HIV. *AIDS and Behavior*, *30*, 1577-1588. https://doi.org/10.1007/s10461-025-04971-w

Degroote, S., Vogelaers, D., & Vandijck, D. M. (2014). What determines health-related quality of life among people living with HIV: An updated review of the literature. *Archives of Public Health, 72*(1), 40. https://doi.org/10.1186/2049-3258-72-40

Desta, A., Biru, T. T., & Kefale, A. T. (2020). Health related quality of life of people receiving highly active antiretroviral therapy in Southwest Ethiopia. *Ploa One, 15*(8), e0237013. https://doi.org/10.1371/journal.pone.0237013

Dzramado, V. L., Oduro, E., & Lasim, O. U. (2026). Applying convergent parallel mixed methods design to investigate medication adherence among people living with HIV in resource-limited settings: Methodological insights from Ghana. *Frontiers in Public Health, 14*, 1776541. https://doi.org/10.3389/fpubh.2026.1776541

Fekete, E. M., Williams, S. L., & Skinta, M. D. (2018). Internalised HIV-stigma, loneliness, depressive symptoms and sleep quality in people living with HIV. *Psychology & Health, 33*(3), 398-415. https://doi.org/10.1080/08870446.2017.1357816

Golin, C. E., Knight, K., Carda-Auten, J., Gould, M., Groves, J. S., White, B. L., Bradley-Bull, S., Amola, K., Fray, N., Rosen, D. L., Mugavaro, M. J., Pence, B. W., Flynn, P. M., & Wohl, D. A. (2016). Individuals motivated to participate in adherence, care and treatment (imPACT): development of a multi-component intervention to help HIV-infected recently incarcerated individuals link and adhere to HIV care. *BMC Public Health*, *16*(1). https://doi.org/10.1186/s12889-016-3511-1

Holtzman, C. W., Brady, K. A., & Yehia, B. R. (2015). Retention in Care and Medication Adherence: Current Challenges to Antiretroviral Therapy Success. *Drugs*, *75*(5), 445–454. https://doi.org/10.1007/s40265-015-0373-2

Hutton, V. E., Misajon, R., & Collins, F. E. (2013). Subjective wellbeing and "felt" stigma when living with HIV. *Quality of Life Research, 22*(1), 65-73. https://doi.org/10.1007/s11136-012-0125-7

Hyle, E. P., Wattananimitgul, N., Mukerji, S. S., Foote, J. H. A., Reddy, K. P., Thielking, A., Yu, L., Viswanathan, A., Rubin, L. H., Shebl, F. M., Althoff, K. N., & Freedberg, K. A. (2024). Age-associated dementia among older people aging with HIV in the United States: A modeling study. *AIDS, 38*(8), 1186-1197. https://doi.org/10.1097/QAD.0000000000003862

Iheagwara, C., Ezulike, S., Anja, M., & Okobi, O. E. (2025). The latest trends and evolution of HIV medication management: A systematic review. *Cureus, 17*(9), e91933. https://doi.org/10.7759/cureus.91933

Karugaba, G., Thupayagale-Tshweneagae, G., Moleki, M. M., & Matshaba, M. (2023). Challenges and coping strategies among young adults living with perinatally acquired HIV infection in Botswana: A qualitative study. *Plos One, 18*(4), e0284467. https://doi.org/10.1371/journal.pone.0284467

Koku, E. F. (2024). The effect of stigma and social networks on role expectations among African immigrants living with HIV. *International Journal of Environmental Research and Public Health, 21*(6), 782. https://doi.org/10.3390/ijerph21060782

Lazarus, J. V., Safreed-Harmon, K., Kamarulzaman, A., Anderson, J., Leite, R. B., Behrens, G., Bekker, L. G., Bhagani, S., Brown, D., Brown, G., & Buchbinder, S. (2021). Consensus statement on the role of health systems in advancing the long-term well-being of people living with HIV. *Nature Communications, 12*(1), 4450. https://doi.org/10.1038/s41467-021-24673-w

Mgbere, O., Rodriguez-Barradas, M. C., Vigil, K. J., McNeese, M., Tabassam, F. H., Barahmani, N., Wang, J., Arafat, R. R., & Essien, E. J. (2018). Systemic Delays in the Initiation of Antiretroviral Therapy for Clinically Eligible HIV-Infected Patients in Houston, Texas. *Journal of the International Association of Providers of Aids Care (JIAPAC)*, *17*. https://doi.org/10.1177/2325958218774042

Mohammed, S. A., Yitafr, M. G., Workneh, B. D., & Hailu, A. D. (2021). Health-related quality of life and associated factors among people living with human immunodeficiency virus on highly active antiretroviral therapy in North East Ethiopia: Cross-sectional study. *Plos One, 16*(3), e0247777. https://doi.org/10.1371/journal.pone.0247777

Nkulu-Kalengayi, F. K., Ouma, A. A., & Hurtig, A. K. (2026). "I have many burdens": Experiences and perceptions of vulnerabilities, healthcare, and support among PLHIV in Sweden: A qualitative interview study. *AIDS Care, 38*(4), 701-715. https://doi.org/10.1080/09540121.2025.2584612

Nuwahereza, D., Nabisere, A., Namatovu, I., Ngabirano, T. D., & Osingada, C. P. (2026). Crests, troughs, and plateaus: Using story theory to explore the experiences of adolescents and young people living with HIV in Kampala, Uganda. *Plos One, 21*(3), e0345499. https://doi.org/10.1371/journal.pone.0345499

Obeagu, E. I., & Alsadi, R. A. (2025). From diagnosis to acceptance: Mental health trajectories in HIV-infected patients. *Universal Journal of Pharmaceutical Research*. *10*(2), 79-90. https://doi.org/10.22270/ujpr.v10i2.1324

Okonji, E. F., Wyk, B. V., & Mukumbang, F. C. (2022). Applying the biopsychosocial model to unpack a psychosocial support intervention designed to improve antiretroviral treatment outcomes for adolescents in South Africa. *Pan African Medical Journal*, *41*. https://doi.org/10.11604/pamj.2022.41.166.31985

Owusu, A. Y. (2022). Experiences of new diagnoses among HIV-positive persons: Implications for public health. *BMC Public Health, 22*(1), 538. https://doi.org/10.1186/s12889-022-12809-6

Poku, O. B., Eschliman, E. L., Entaile, P., Rampa, S., Mehta, H., Tal, D., Silvert, L., Li, T., Becker, T. D., Govindasamy, D., & Stockton, M. A. (2023). "It's better if I die because even in the hospital, there is a stigma, people still gossip": Gossip as a culturally shaped labeling process and its implications for HIV-related stigma in Botswana. *AIDS and Behavior, 27*(8), 2535-2547. https://doi.org/10.1007/s10461-023-03980-x

Poku, O. B., West, N. S., Eschliman, E. L., Dangerfield, D. T., Bass, J., Kennedy, C. E., & Murray, S. M. (2023). Mental health problems across the HIV care continuum for adolescents living with HIV in sub-Saharan Africa: A scoping review. *AIDS and Behavior, 27*(8), 2548-2565. https://doi.org/10.1007/s10461-023-03981-w

Pollak, C., Cotton, K., Winter, J., & Blumen, H. (2025). Health outcomes associated with loneliness and social isolation in older adults living with HIV: A systematic review. *AIDS and Behavior, 29*(1), 166-186. https://doi.org/10.1007/s10461-024-04471-3

Portilla-Tamarit, I., Rubio-Aparicio, M., Fuster-RuizdeApodaca, M. J., Portilla-Tamarit, J., Reus, S., & Portilla, J. (2024). Health-related quality of life in people with advanced HIV disease, from 1996 to 2021: Systematic review and meta-analysis. *AIDS and Behavior, 28*(6), 1978-1998. https://doi.org/10.1007/s10461-024-04298-y

Quinn, K., Reed, S. J., Dickson-Gómez, J., & Kelly, J. A. (2018). An Exploration of Syndemic Factors That Influence Engagement in HIV Care Among Black Men. *Qualitative Health Research*, *28*(7), 1077–1087. https://doi.org/10.1177/1049732318759529

Rzeszutek, M., Gruszczyńska, E., Grabowska, M., Malinowska, P., & Sosińska, B. (2026). Relationship quality among people living with HIV/AIDS: A systematic review and meta-analysis. *24*, 82. https://doi.org/10.1186/s12955-026-02555-3

Safreed-Harmon, K., Anderson, J., Azzopardi-Muscat, N., Behrens, G. M., Monforte, A. D. A., Davidovich, U., Del Amo, J., Kall, M., Noori, T., Porter, K., & Lazarus, J. V. (2019). Reorienting health systems to care for people with HIV beyond viral suppression. *The Lancet HIV, 6*(12), e869-e877. https://doi.org/10.1016/S2352-3018(19)30334-0

Sosnowski, R., Kulpa, M., Ziętalewicz, U., Wolski, J. K., Nowakowski, R., Bakuła, R., & Demkow, T. (2017). Basic issues concerning health-related quality of life. *Central European Journal of Urology, 70*(2), 206-211. https://doi.org/10.5173/ceju.2017.923

Tenkorang, E. Y., & Owusu, A. Y. (2026). Food insecurity over the life course and intimate partner violence among women living with HIV/AIDS in Ghana. *Sociological Inquiry, 96*(2), 361-380. https://doi.org/10.1111/soin.70023

Tran, N. K., Vu, B. N., Susa, J., & DeSilva, M. (2022). Stigma, coping strategies, and their impact on treatment and health outcomes among young men living with HIV in Vietnam: A qualitative study. *PLOS Global Public Health, 2*(9), e0000669. https://doi.org/10.1371/journal.pgph.0000669

Vu, G. T., Tran, B. X., Hoang, C. L., Hall, B. J., Phan, H. T., Ha, G. H., Latkin, C. A., Ho, C. S., & Ho, R. C. (2020). Global research on quality of life of patients with HIV/AIDS: Is it socio-culturally addressed?. *International Journal of Environmental Research and Public Health, 17*(6), 2127. https://doi.org/10.3390/ijerph17062127

Wanjala, S. W., Nyongesa, M. K., Mapenzi, R., Luchters, S., & Abubakar, A. (2023). A qualitative inquiry of experiences of HIV-related stigma and its effects among people living with HIV on treatment in rural Kilifi, Kenya. *Frontiers in Public Health, 11*, 1188446. https://doi.org/10.3389/fpubh.2023.1188446

WHOQOL Group. (1995). The World Health Organization quality of life assessment (WHOQOL): Position paper from the World Health Organization. *Social Science & Medicine, 41*(10), 1403-1409. https://doi.org/10.1016/0277-9536(95)00112-K

Xu, J. F., Ming, Z. Q., Zhang, Y. Q., Wang, P. C., Jing, J., & Cheng, F. (2017). Family support, discrimination, and quality of life among ART-treated HIV-infected patients: a two-year study in China. Infectious diseases of poverty, 6(1), 152. https://doi.org/10.1186/s40249-017-0364-5

Zahra, A. N., Waluyo, A., Yona, S., & Pakasi, T. A. (2024). Resilience in relation to adherence to antiretroviral therapy in people living with HIV: A qualitative study. *Global Qualitative Nursing Research, 11*, 23333936241233449. https://doi.org/10.1177/23333936241233449

Zhang, C., & Zhang, Y. (2025). Selective disclosure and different levels of support: Strategies for managing intersectional stigma in HIV healthcare engagement. *AIDS Care, 37*(11), 1978-1989. https://doi.org/10.1080/09540121.2025.2570403

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