

Understanding HIV service preferences of South African women 30–49 years old missing from or linked to care: An exploratory study of Gauteng and Limpopo provinces

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Aneesa Moolla^{1,2,*}, Michael Galvin^{1,2,3,4,*} ,
Constance Mongwenyana^{1,2} , Jacqui Miot^{1,2} ,
William Magolego^{1,2}, Patricia Leshabana^{1,2}, Nkosinathi Ngcobo^{1,2},
Nalini Naidoo^{1,2} and Lezanie Coetzee^{1,2}

Abstract

Background: The HIV epidemic in sub-Saharan Africa has a disproportionate gender impact, with women bearing the brunt of the epidemic. South Africa carries the largest share of the global HIV burden, with similar trends seen for women due to unequal socio-cultural and economic status.

Objectives: This study aims to understand 30–49-year-old women's barriers and facilitators to accessing HIV services in order to maximize health in resource limited settings and reach women missing from HIV care.

Design: Employing a convenience sampling strategy, we recruited, informed, and consented participants at clinics and public areas. Interviews were conducted in respondent's preferred languages, transcribed verbatim, translated into English if needed, and thematically analyzed using grounded theory.

Methods: We conducted 81 interviews with women aged 30–49 either missing from care ($n=21$), having unknown HIV status ($n=30$) or linked to care ($n=30$) within two sites: City of Johannesburg district, Gauteng Province and Mopani district, Limpopo Province.

Results: Participants missing from care reported negative staff attitudes, queues, family rejection, medication side effects, and painful blood tests as key deterrents. Participants with an unknown status were deterred by fear of being diagnosed as HIV positive and family rejection, which was similar to women missing from care who often dropped out from care due to actual family rejection. Participants linked to care reported that long queues and staff shortages were challenges but stayed in care due to a will to live for themselves and their children, in addition to counselling and feeling emotionally supported. Interestingly, participants missing from care often accessed medication from friends but, similarly to those with unknown status, noted that they would access care if attended to by supportive nurses and by having non-clinical HIV services.

Conclusions: The accounts of women in this research highlight significant improvements needed to address inequities in the fight against HIV in South Africa. Additionally, the healthcare service access preferences of women aged 30–49 need to be further explored quantitatively in order to design policy relevant interventions.

¹Health Economics and Epidemiology Research Office, Johannesburg, South Africa

²Health Sciences Research Office, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa

³Department of Psychiatry, Boston Medical Center (BMC), Boston, MA, USA

⁴T.H. Chan School of Public Health, Harvard University, Boston, MA, USA

*These authors contributed equally to this work.

Corresponding author:

Michael Galvin, Health Economics and Epidemiology Research Office, Johannesburg 2193, South Africa.
Email: michaelgalvin@wustl.edu



Plain language summary

Understanding HIV service preferences of South African women 30–49 years old missing from or linked to care: An exploratory study of Gauteng and Limpopo provinces

The HIV epidemic in sub-Saharan Africa harms women more than men. South Africa carries the largest share of the global HIV burden, with similar trends seen for women. This study aims to understand 30–49-year-old women's ability to access HIV services in order to reach women missing from HIV care. We conducted 81 interviews with women aged 30–49 either missing from care ($n=21$), having unknown status ($n=30$) or linked to care ($n=30$) within two sites: City of Johannesburg district, Gauteng Province and Mopani district, Limpopo Province. We recruited, informed, and consented participants at clinics and public areas. Interviews were conducted in respondent's preferred languages, transcribed, and translated into English for analysis. Participants missing from care reported negative staff attitudes, queues, family rejection, medication side effects and painful blood tests as key deterrents. Participants with an unknown status were deterred by fear of being diagnosed as HIV positive and family rejection, which was similar to women missing from care who often dropped out from care due to family rejection. Participants linked to care reported that long queues and staff shortages were challenges but stayed in care due to a will to live for themselves and their children, in addition to counselling and feeling emotionally supported. Interestingly, participants missing from care often accessed medication from friends but, similarly to those with unknown status, noted that they would access care if attended to by supportive nurses and by having non-clinical HIV services. The healthcare service access preferences of women aged 30–49 needs to be further explored in order to improve interventions.

Keywords

HIV, South Africa, women, missing from care

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Introduction

More than four decades into the HIV/AIDS crisis, an estimated 37.9 million people around the world are infected with HIV, with sub-Saharan Africa (SSA) accounting for 68% of the global burden.¹ One unchanging feature of the HIV epidemic in SSA has been the disproportionate gender impact, as women in SSA continue to bear the brunt of the epidemic relative to their male counterparts.² South Africa carries the largest share of the global HIV burden, and the HIV epidemic disproportionately affects women compared to men because of their unequal cultural, social, and economic status in society, as well as due to continued failures in the local healthcare systems.^{2–4} The regions of East and Southern Africa are the most affected by HIV, with over 700,000 new infections in 2019.⁵ South Africa is the world's worst affected country with approximately 7.9 million people of all ages living with HIV in 2017.⁶ Among adults aged 15–49 years, HIV prevalence was 20.6% (26.3% among women and 14.8% among men) highlighting the importance of ensuring women in particular can prevent and treat HIV.⁷ Furthermore, in South Africa, the generally low socioeconomic status of women reinforces unequal gender and age power dynamics, often leading them into relationships that expose them to a higher risk of HIV infection than men, by engaging in risky sexual behaviors such as transactional and intergenerational sex.^{8,9}

Although gender dynamics may differ slightly across SSA, there are many commonalities which increase

women's vulnerability.¹⁰ As highlighted, these unequal power relationships between women and men are pervasive but can also contribute to women's risk of HIV transmission,^{10–12} as they affect sexual decision-making and the ability of women to use condoms.¹¹ Even in other sub-regions of East, West, and Central Africa, the population most affected by HIV are women, which can largely be attributed to the same unequal cultural, social, and economic status for women in these societies.¹³ Inequitable laws and harmful traditional practices reinforce unequal power dynamics between men and women, with women particularly disadvantaged.¹⁴ HIV is not only driven by gender inequality, but it also entrenches gender inequality, leaving women more vulnerable due to its impact.¹⁵ Women living in rural settings are at a greater risk due to gender norms and traditional roles that exacerbate women's inferiority, with even less power to protect themselves from HIV infection as they are often dependent on men and live further from biomedical health services.^{16,17} Additionally, several studies have identified the age range of women in their 30s and 40s as an important period for HIV testing and care, as this population group carries a disproportionately higher HIV disease burden as compared to males in this age group – and both females and males across other age groups.^{18–20} Therefore, research into understanding and reaching South African women in this age group who are missing from HIV care and treatment due to the vulnerabilities discussed above is critically needed to align the needs of women with the UNAIDS' "95–95–95" targets.

HIV services are central to the Sustainable Development Goal of ending AIDS by 2030 and to UNAIDS' "95–95–95" targets aimed at ensuring that, by 2025, 95% of all people living with HIV will know their HIV status; 95% of all people with diagnosed HIV will access treatment; and 95% of all people receiving ART will achieve viral suppression.¹⁷ Women continue to face difficulties, both at home and in healthcare settings when trying to access HIV services.²¹ Policymakers are increasingly aware that these barriers act as obstacles to HIV services such as treatment access and adherence.¹⁵ To date, however, there has been scant formal evidence, from women's own perspectives, regarding if and how this gender-based inequalities and other related factors affect women's ability to access, start, and continue with HIV services.¹⁷ Seeking strategies to help those women facing challenges to access HIV services is essential to enhance understanding of the experiences of these women. In addition, to maximize women's health in resource limited settings, it would be beneficial for policy and program makers to understand more about facilitators and barriers to HIV services for women, from women's own perspectives. This study sought to identify the characteristics of HIV services that are important to 30–49-year-old South African women when making decisions regarding whether to and how to access care.^{18–20}

Methods

Study design

Our overarching aim is to understand the preferences of women in the Gauteng and Limpopo provinces of South Africa—particularly those women who are missing from care—for accessing and utilizing HIV care and treatment services across the HIV care continuum. Additionally, we seek to determine how models of care might target those women who are currently missing from HIV care and treatment services. This cross-sectional, qualitative study used a convenience sampling strategy to identify potential participants across several sites. Fieldworkers approached women in the age bracket, introduced the study, and asked them if they are interested in doing a key informant interview. New participants were no longer recruited once saturation was achieved indicating no new emerging themes. Authors completed the Consolidated Criteria for Reporting Qualitative Research (COREQ) a 32-item checklist, which covers the reporting of studies using interviews and focus groups.

Study sites

The study lasted 12 months beginning in November 2021. It recruited and enrolled women from: (1) public healthcare settings (e.g., clinics) where they were already seeking HIV or other healthcare services; (2) other spaces visited by women aged 30–49 years old who may not

traditionally seek care at public sector primary healthcare facilities. The focus was to not only include women who are already accessing HIV services (at healthcare clinics) but also to include women who have an unknown status or who are living with HIV but not accessing care. This process was completed using the same process as at the healthcare clinics, namely, women in the public areas from the specific age bracket were approached by fieldworkers. Fieldworkers were trained in study protocols and able to speak with potential participants in the language of their choice. These settings were identified through a process of observation and consultation with stakeholders and included (but were not limited to) shopping malls, factories, taxi ranks, homeless shelters, hostels, churches, and sports venues in both the Gauteng province and the Mopani district, Greater Tzaneen sub-district, in the Limpopo province in South Africa. The women at these sites were approached and asked if they were willing to be informed about the study. Women were excluded if they were unable or unwilling to complete the interview. Participants' HIV status was shared during interviews if the participants decided to do so. It was not part of eligibility to participate to share HIV status. All participant interviews were collected via audio recording and transcribed verbatim (then translated if required).

Informed consent

Written informed consent was requested from participants, including a separate audio consent form. This process could be completed in English or isiZulu. All participants who were willing to participate received a copy of the Information Sheet containing information about the purpose of the study and participant rights. A trained interviewer was available to review this document with the participants. Participants were asked if they had any follow-up questions to ensure that the informed consent process had been adequately understood by participants. If they agreed to participate, they were asked to sign a copy of the informed consent form and audio-recording consent form. This form sought consent for the interviews and recording thereof, and a copy of this was retained as part of the study. Participants also retained a signed copy if they chose to. Importantly, participants who were willing to be in the study, but not be recorded, were still enrolled but no recording was done. In these instances, comprehensive notes were taken to ensure that all information was captured adequately and as comprehensively as possible. Field notes and a reflective journal were also kept for all participants and used during the data collation process.

Interviews

After consent was obtained, the individual was assigned a unique study identification (ID), and participant name and study ID were entered into the study register. The study ID

was used for all data collection and the participant's name was recorded on data collection forms. All of these interviews focused on patient preferences for health services and were conducted using a semi-structured questionnaire, lasting approximately 30–60 min. Individuals were recruited directly from sites listed above and enrolled if they gave consent, with the interview following directly after consent. The number of individuals contacted, their willingness to participate, and actual participation was tracked in a log.

Reimbursements for participant time

Due to the fact that participation in the interviews involved participants taking time away from work or looking for work or potentially taking time away from home duties after work hours, they were reimbursed ZAR150 (around US\$10) for their time regardless of labor force participation. This rate is informed by the time taken to complete the interview and the minimum wage rates outlined in South Africa, and factors in the inconvenience of participating in the interview without the risk of unfairly influencing anyone to participate.

Data handling

Participant confidentiality was essential to the protection of human subjects and obtaining accurate information for this specific study. Thus, access to subject information was limited to the study team, and all data were stored in password-protected files. For all data collection methods, the participants were assigned a study ID number. Because we did not collect any personal identifiers, there was minimal risk of loss of subject confidentiality.

The study database containing the processed interview responses was organized by the assigned study ID number and did not contain identifying information. Interview recordings were transcribed verbatim either by a transcription company or by internal staff and translated into English if needed. Health Economics and Epidemiology Research Office (HE²RO) researchers conducted quality assurance measures to ensure that the transcripts were complete and accurate. The recordings, transcripts, and study database were stored on password-protected computers at HE²RO. The computers containing the study database are kept in a locked office at HE²RO when not in use by the study team. All database files are password-protected, and only study staff have access to the files. Hard copy documentation is stored in locked cabinets in the offices of HE²RO. Upon completion of the final interviews, hard copies of documentation (interview guides, information sheets, and consent forms) were scanned and saved on secure computer servers only accessible to the HE²RO research team. The electronic copies of the originals will be kept for 7 years after study completion before

destroying them. Audio files were destroyed within 1 month of completing analysis of the interview data.

Data analysis

We used NVivo 11 qualitative software to manage the transcribed data. We established a preliminary codebook framework *a priori* and then followed an inductive, grounded theory analysis process, allowing new codes to emerge from the data. The codebook was updated iteratively in regular feedback sessions with the coding team. The interview transcripts were coded using the same “master” codebook to allow for comparability across interview types. Transcripts were coded by two study team members, and NVivo's intercoder comparison functionality was used to ensure inter-coder reliability. The results were summarized by theme (and cross-cutting themes) and included individual quotations and experiences. Ethical oversight was provided by the Human Research Ethics Committee (Medical) at the University of the Witwatersrand (M211179).

Results

Participant characteristics

We conducted 81 interviews with women aged 30–49 either HIV positive and missing from care (HPM) ($n=21$), had an unknown HIV status (HU) ($n=30$) or were HIV positive and linked to care (HPL) ($n=30$) within two sites: City of Johannesburg district, Gauteng Province and Mopani district, Limpopo Province. All participants were cis-gender women. Out of the 81 participants, most women 95.1% (HPL=93.3%, HPM=95.2% and HU=70%) were black and 64.2% (HPL=56.7%, HPM=66.7% and HU=64.2%) were between the ages of 30 and 40 years with a median age of 40.5 years (Table 1). The majority of the participants 69.1% (HPL=83.3%, HPM=71.4% and HU=50%) had attended high school, and this group contained the highest number of women linked to care (28/30). A total of 46.9% (HPL=43.3%, HPM=42.9% and HU=53.3%) of the participants reported that they were single while 27.7% (HPL=40%, HPM=9.5% and HU=26.7%) indicated they were married. Over half of all the women 55.6% (HPL=53.3%, HPM=81.0% and HU=40%) also reported that they were unemployed (of which the greatest number were missing from care (17/21)).

Qualitative findings

Based on the findings, characteristics of HIV services that are important to 30–49 year-old South African women when making decisions regarding whether and how to access care include the following: services that are

Table 1. Demographics.

Variables	HPL (n = 30)	HPM (n = 21)	HU (n = 30)	Total 81 (n = 30)
Age (years)				
30–39	14 (46.7%)	14 (66.7%)	19 (63.3%)	47 (58.0%)
40–49	16 (53.3)	7 (33.3)	11 (36.7)	34 (42.0)
Mean	15	10.5	15	40.5
Race				
Black	28 (93.3)	20 (95.2)	29 (96.7)	77 (95.1)
Other	2 (6.7)	1 (4.8)	1 (3.3)	4 (4.9)
Education				
Primary school	2 (6.7)	5 (23.8)	2 (6.7)	9 (11.1)
High school	25 (83.3)	15 (71.4)	15 (50.0)	56 (69.1)
Post-secondary/vocational training	2 (6.7)	—	8 (26.7)	10 (12.3)
University Bachelor's degree	—	—	1 (3.3)	1 (1.2)
University Postgraduate	—	—	1 (3.3)	1 (1.2)
No attended school	1 (3.3)	—	—	1 (1.2)
Relationship				
Single	13 (43.3)	9 (42.9)	16 (53.3)	38 (46.9)
In a relationship	1 (3.3)	5 (23.8)	3 (10.0)	9 (11.1)
Married	12 (40.0)	2 (9.5)	8 (26.7)	22 (27.2)
Widowed	1 (3.3)	3 (14.3)	—	4 (4.9)
Divorced	1 (3.3)	—	1 (3.3)	2 (2.5)
Separated	1 (3.3)	1 (4.8)	—	2 (2.5)
Employment				
Employed	10 (33.3)	2 (9.5)	17 (56.7)	29 (35.8)
Unemployed	16 (53.3)	17 (81.0)	12 (40.0)	45 (55.6)
Self-employed	1 (3.3)	1 (4.8)	1 (3.3)	3 (3.7)
Unknown	3 (10.0)	1 (4.8)	—	4 (4.9)

HPL: HIV positive and linked to care; HPM: HIV positive and missing from care; HU: Unknown HIV status.

efficient and do not take too much time to access, services that treat them with respect and care, and services that work to minimize the stigma of HIV. Although all participants reported that queues, family rejection, and staff shortages were deterrents, participants who were missing from care were more consistent about how it was a cascade of factors that discouraged them from returning to seek HIV care again. Women who remained untested for HIV highlighted that this was largely due to fears of an HIV diagnosis and potential family rejection (Figure 1).

Staff shortages, long queues, and wait times to access care

One of the largest concerns among all participants—both those linked to care and those missing from care—was the issue of long wait times in accessing treatment. Patients reported varying wait times, ranging from an average of 2–5 h, with others saying they regularly had to spend the entire day in the queue waiting to be consulted by a health-care worker.

Another participant remarked that sometimes you can wait the entire day for care without even receiving any services at all.

I can go now [to the clinic] at 7am and maybe stay until around 5pm without being helped (HPL 17)

Participants attributed these long waits to several factors; however, shortages among medical staff were one of the primary reasons from the patient perspective.

Participants also noted how at times staff would take extended lunch breaks which would cause additional wait times for patients.

When they [health workers] get to the clinic you find that they went for lunch at one and they were supposed to come back at two. But instead they will come back at half past two or three and at four they will knock off (HU 22)

The difficulties of long wait times are particularly acute for patients who have jobs and cannot take time off to pick up their HIV medications. As clinics are not open on the weekends, patients are often required to take a full day off of work to wait in line at the clinic.

Difficult patient–provider interactions

In addition to long wait times, participants both linked to care and missing from care also described how health

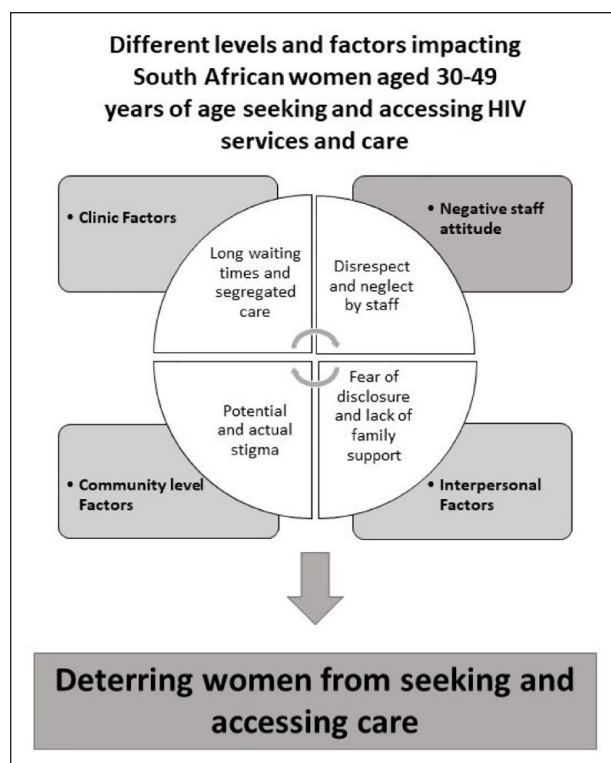


Figure 1. Barriers to seeking care among women aged 30–49 years.

workers often treated them poorly. This includes health workers raising their voices at patients and other disrespectful acts such as “*insults*” (HPM 17).

In addition to arriving late for an appointment, other participants noted how health workers will also aggressively scold patients if they come on the wrong day.

Sometimes I’ll miss my scheduled visit one day and when I arrive there the following day, instead of talking nice with me they will shout at me in front of people; and some of the things they say are things they are not supposed to be saying to us patients. Hence people who are sick end up not going to the clinic and prefer to die with their sickness just because the nurses don’t treat us well. . . We are also human beings we don’t deserve to be treated as such (HPM 12)

Patients who were missing from care noted that they were at times “*too scared to go to the clinic*” because of staff behavior (HPM 11). Due to this poor treatment by staff, patients missing from care described how they would share HIV medication with others simply to avoid having to go to the clinic.

I skipped my scheduled visit date, maybe 2 or 3 months [in a row], and they [health workers] shouted at me so much that I ended up deciding “let me leave this” [stop treatment]. In December 2019, I went back home in Eastern Cape. I tried to go there to restart my treatment but they wanted a transfer

letter from me, so I couldn’t come back [to Johannesburg] just for that letter so I stayed at home for the whole year. I went back after a year and they shouted me even more so I just stop going there. So, there is my sister who is on treatment and she shares hers [HIV medications] with me (HPM 06)

It is important to note, however, that not all patients found health workers to treat them badly. One patient who is still linked to care described health workers as an important source of health and encouragement in their treatment journey.

Nurses won’t tell you to stop taking medications. They are the ones helping us and encouraging us to come and stand everyday here so we can be healthy (HPL 07)

Stigma

There are many ways in which patients linked to care described the stigma of HIV being a barrier to treatment. Several patients described going to clinics far from their homes so as to avoid being seen by anyone they know.

I’m not supposed to be collecting my treatment here, I’m supposed to be collecting my treatment in Ivory Park Clinic. But the problem is I fear people and those from the community who do not know [I am HIV-positive]. They will start talking about how they’ve been seeing me at the clinic to collect such and such. So, to avoid being looked at like that by people and to be on the safe side, I decided to collect my treatment elsewhere. (HPL 29)

Other patients reported that due to the need to access care far from home, it was often difficult to find the extra money to pay for the additional transport costs. One patient currently missing from care described how stigma of seeking care near home led her to visit clinics far away from her neighborhood, thus leading to extra costs and eventually defaulting from treatment.

The issue of transport fee is the main reason I don’t go to the clinic because I have to take 3 taxis. I don’t go to the nearest clinic within my area, I go to the one that’s very far, it’s because of these scandals around my community you know when you have a partner and you are both positive in the community (HPM 11)

As misinformation about HIV is still common in many communities, patients go to great lengths to avoid disclosing their status to their friends, neighbors, and family members to avoid being stigmatized.

One day I visited my brother and when I was feeding my child and theirs and his wife was saying I should not feed my child with the same spoon as theirs because my child will infect

their child since I am HIV positive. I even cried because my child is not even HIV positive (HPM 07).

Due to this stigma against people living with HIV, patients with an unknown HIV status often reported not wanting to get tested due to fears of an HIV diagnosis and potential family rejection.

Many patients described how clinics often further stigmatize patients via the practice of segregating HIV-positive patients from HIV-negative patients. When arriving for their appointment, participants reported being told to stand in a queue with only other HIV-positive patients thereby divulging their status to everyone around them.

When we get there [to the clinic], they separate us by our sickness. They shout that “you guys on ARVs who come to do your blood tests must stand here.” That makes us feel very bad and not like other people. . . at least if we were waiting in one queue like everyone no one should know about our sickness (HPM 07)

Lastly, participants also reported stigma and delayed treatment for HIV as being related to traditional African conceptions of illness, such as bewitchment.

Some patients, they’ll say they are sick because it’s witchcraft. We do tell them there is no witchcraft, go to the clinic (HPM 04)

There were significant differences between patients based on their status and relationship to treatment. Even though almost all participants found wait times, stigma, staff shortages, and poor treatment by clinic staff to be deterrents to seeking care, participants who were missing from care were more consistent about how it was a cascade of factors that dissuaded them from returning to seek HIV care. The entire process of accessing care was described as time-consuming and laborious due to long clinic waiting times, and this was compounded by feelings of turmoil if these women then felt disrespected and neglected by clinic staff. Overarching these factors were fears of disclosure due to potential and actual stigma from their community, family, and/or friends. Results indicate that this combination of deterrents was most likely to end clinic visits for women aged 30–49 years. All key themes and subthemes identified and used in this study’s codebook are listed in Table 2.

Interestingly, the will to survive of these participants, often a motivating factor amongst women seeking care, was still present as this complex web of factors compelled them to seek out alternate strategies which included accessing medication from friends. Some further noted that they know others who would rather die than return to a clinic mode of care. Notably, there was a similarity to those with unknown statuses who indicated that they would access care if they could attend non-clinic HIV services which were staffed by supportive healthcare workers.

Table 2. Key themes.

Themes	Sub-themes
Women 30–49 treatment success or failure	Screening facilitators Facilitators to stay in care Barriers to staying in care
Women 30–49 HIV testing	Major barriers to overcome Facilitators Barriers
Home life	Work life balance Unemployment Roles Number of children House members
HIV status	Willingness to disclose status Treatment ongoing Time of test Start of treatment Treatment facilitators Treatment barriers Adherence
Facilitators for visiting clinics	Time Appointment
Facilitators during clinic visits	HIV diagnosis and treatment information Healthcare worker friendliness Emotional wellbeing support
Demographics	Race Marital status Highest education level Gender Employment Age
Clinic visits	Specify services In the last 6 months or very recently During Covid Before Covid
Characteristics of HIV services that influence decision to access care	
Characteristics HIV services that influence decision how to access care	
Barriers to HIV services	
Barriers to visiting clinics	Work Stigma Money Children
Barriers during clinic visits	Queues Healthcare workers

Discussion

This study examining the perspectives of 30–49 year-old women in Gauteng and Limpopo Province, South Africa highlighted important barriers to HIV testing and

treatment. Among the 81 women interviewed for this study, 21 were HIV positive women who were not accessing care or were missing from care, 30 were women who did not know their HIV status, and 30 were women who were linked to and retained in care. Other significant research has examined the barriers to testing and treatment in an attempt to identify best practices for retaining people in care.²² Among the most significant barriers to treatment in this research, women described staff shortages leading to long wait times for services, difficult patient–provider interactions, and significant stigma surrounding HIV and the administration of testing and treatment. Although many studies examining barriers to HIV testing and treatment for women focus on specific populations such as pregnant women or female sex workers, this study was unique as it examined women in general.^{23–25} These studies therefore highlight important structural factors that impact care seeking behaviors not only for middle-aged women but for HIV patients more broadly.

Staff shortages and long wait times

Staff shortages and long wait times have been identified as a significant impediment to ART adherence around the world.²³ Several recent studies in South Africa have highlighted how shortages in clinical staff and long queues for patients represent significant barriers to both HIV prevention and treatment services throughout the country, with women experiencing particular hardship.^{26,27} This situation is likely to have worsened during COVID-19 leading many to consider wait times a considerable barrier to service usage.²⁸

Similar to the findings in this research, patients in other South African studies argued that wait times tended to last several hours to a full day and were a significant contributor to high levels of dissatisfaction with clinic services, leading them to be more likely to stop coming to the clinic to pick up their medications.^{29,30} One study in Durban, South Africa found that patients renewing HIV medications had to wait in four separate queues, and patients waiting for blood tests or a doctor's visit waited in up to seven different queues.³¹ In this same study, even patients in the "fast track" waited in four queues and had a mean total visit time of 2 h and 26 min. Meanwhile, the mean clinic appointment duration with a nurse was only 7 min or equivalent to only 5% of the total visit time.³¹ This highlights chronic structural conditions in HIV services that act as barriers to patients seeking HIV treatment.

However, these results for HIV services are not unusual in South Africa or the region. For example, across chronic conditions, patients in South Africa have reported long wait times and understaffing to be a significant reason as to why they are dissatisfied with care.³² Similarly, in other countries in southern Africa, such as Zambia, patients have similarly cited staff shortages and long wait

times as a reason for defaulting on adherence to ART medications.³³ Therefore, these problems appear systemic and will require significant changes in order to improve patient satisfaction.

Difficult patient–provider interactions

Similar to the problem of staff shortages and long wait times for care, patients in this study identified difficult interactions with nurses and other healthcare providers as a significant barrier to seeking testing and treatment services. There exists an extensive body of literature on nurse–patient interactions and communication which has been widely cited both for HIV care and non-HIV care.³⁴ With regard to HIV however, positive clinical experiences for patients through the development of good quality relationships has been found to promote ART adherence across contexts.³⁵ However, research on patient–provider interactions has tended to focus on the healthcare provider perspective with fewer studies examining the perspective of patients.³⁶

Nevertheless, a few studies have highlighted the role that negative provider attitudes can have on patients in HIV settings in South Africa.^{29,37,38} In addition, studies in other settings—both in SSA and globally—have similarly highlighted this phenomenon.^{33,39–41} Often described in the context of "interpersonal issues," these studies describe patients not adhering to ART due to "staff rudeness" including "scolding, insulting language, not being provided services, nor being treated with dignity, particularly during delivery".⁴⁰ Other patients describe experiences of harassment by nurses which make them unwilling to return for further treatment.³⁸

One in-depth study on this question in neighboring Zimbabwe described how nurses and other healthcare providers are in a powerful position compared to their rural and often poor and uneducated patients.⁴² The study goes on to describe how nurses can instill fear in patients, leading them to delay going to the clinic for as long as possible and thereby undermining ART adherence. Similar to our study, this research noted emotionally distressing patient–provider interactions including harsh reprimands by nurses which were often linked to ART-related transgressions, such as imperfect adherence or failure to come for a scheduled appointment. The researchers add that as male identity in South Africa is often linked to active rather than passive roles—and that far fewer men come for their appointments than women—men may avoid the clinic in part because they find it difficult to submit to the nurses sometimes "brusque and off-putting treatment".⁴² As our study only included women, the fact that our participants highlighted poor treatment by nurses as a significant reason for medication non-adherence may highlight that poor provider–patient interactions are an even more serious barrier to HIV testing and treatment than other studies show.

Stigma

Stigma has been widely studied both in South Africa and around the globe and is broadly recognized to be one of the primary barriers to HIV testing and treatment.^{43–46} Widely described as a “psychosocial factor” in the South African literature, HIV stigma is intertwined with lack of serostatus disclosure and poor social support as well as HIV-related misconceptions and contributes to low treatment initiation, testing, and care utilization.^{47–49}

One study in South Africa described how stigma emerges as a structural barrier as it prevents patients from disclosing their status to loved ones or others in their social constellation.⁴⁸ Without disclosure, women found they had to attend clinics far away from their homes in order to minimize being identified by members of their community. This fear of disclosure leads to the “secret trade” of ART medications common in South Africa in which patients will share their medications with others to avoid going to the clinic.³⁰ This form of stigma also led many patients to drinking alcohol or substance abuse to cope with the emotional stress they developed from being stigmatized and discriminated against by their friends and some family members.³⁰

Similarly, for patients with an unknown status in South Africa, many would prefer not to know their status as they fear being stigmatized by friends or family members if they find out they are HIV positive.^{50,51} This perceived HIV-related stigma also influences disclosure leading to many people to conceal their HIV status to both family members and sexual partners, thereby leading to a potential perpetuation of the disease.⁵²

In addition to stigma leading patients to delay treatment from clinical settings, other research has highlighted the ways in which patients seek alternative forms of care such as through traditional healers or churches. For example, one study found that local Pentecostal churches in South Africa discouraged patients from seeking care for HIV and AIDS, and instead encouraged patients to be prayed for and thereby cured of the disease.⁴⁸ Similarly, another study found that patients seek care from traditional healers who prepare concoctions for patients to “cleanse their bodies internally” thereby supplementing or eliminating the need for ART medications.³⁰ These cultural factors are important to understand when considering the overall religious-cultural context in which stigma functions as a barrier to care. In terms of limitations, as this study is qualitative and only took place in two of South Africa’s nine provinces, it is therefore not generalizable to the country as a whole.

Conclusion

With rates of HIV nearly twice as high as among men, women in South Africa are faced with a unique burden in preventing HIV infection and seeking treatment if

HIV-positive. The results from this study highlighted three primary ways in which women perceived barriers to testing and treatment, including staff shortages leading to long wait times, difficult patient–provider interactions, and high levels of stigma surrounding HIV. Although many of these factors represent deeply entrenched problems affecting healthcare systems in South Africa in general, understanding how these barriers function to further the epidemic amongst women 30–49 years of age in the country can help promote policy changes to reduce obstacles for women seeking testing or care.

Declaration

Ethics approval and consent to participate

Ethical oversight was provided by the Human Research Ethics Committee (Medical) at the University of the Witwatersrand (M211179). All participants completed informed consent to participate in this study.

Consent for publication

Informed consent for publication was provided by the participants.

Author contributions

Aneesa Moolla: Conceptualization; Methodology; Formal analysis; Writing – review & editing.

Michael Galvin: Writing – review & editing; Writing – original draft; Formal analysis.

Constance Mongwenyana: Writing – review & editing; Formal analysis; Data curation; Supervision.

Jacqui Miot: Supervision; Project administration; Writing – review & editing.

William Magolego: Data curation; Formal analysis; Writing – review & editing.

Patricia Leshabana: Data curation; Investigation; Writing – review & editing.

Nkosinathi Ngcobo: Data curation; Investigation; Writing – review & editing.

Nalini Naidoo: Conceptualization; Methodology; Project administration; Supervision; Writing – review & editing.

Lezanie Coetzee: Supervision; Project administration; Writing – review & editing; Visualization.

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Competing interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Availability of data and material

Data is available upon request from the authors or from the Health Economic & Epidemiology Research Office (HE²RO) at the University of the Witwatersrand which can be reached at information@heroza.org.

Reflexivity statement

This study was completed examining the context of HIV among South African women and was completed primarily by a team of South African women.

ORCID iDs

Michael Galvin  <https://orcid.org/0000-0003-2123-5020>

Constance Mongwenyana  <https://orcid.org/0000-0001-8582-1235>

Jacqui Miot  <https://orcid.org/0000-0001-7070-3826>

Supplemental material

Supplemental material for this article is available online.

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