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## RESEARCH ARTICLE

### Behaviour and Socioeconomic Factors of Undocumented Migrants Missing Antiretroviral Therapy Clinic Appointments in Limpopo Province

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#### Abstract:

##### Background:

Global migration is increasingly driven by socioeconomic and political unrest, raising a potentially challenging burden for healthcare systems. A significant group of non-South African citizens present in the country are undocumented migrants and have not restricted access to healthcare services.

##### Objectives:

This study explored the behaviour and socioeconomic factors of undocumented migrants missing Antiretroviral Therapy clinic appointments.

##### Methods:

A qualitative cross-sectional approach was used. Semi-structured interviews, observations, and document analysis of 17 undocumented migrants, who missed more than four appointments in the first 12 months since antiretroviral therapy initiation, were conducted. Thematic analysis and coding categorised the findings into themes. Reliability and validity were ensured through intercoder agreement, audio recording, triangulation, bracketing, and member checking.

##### Results:

The finding revealed that registering to more than one healthcare facility, self-transfer to another facility, and job hunting resulted in clients missing their scheduled appointments.

##### Conclusion:

The conclusion drawn from this study is that the Electronic Patient Management System must improve to control the number of clients missing clinic appointments.

**Keywords:** Migration, Undocumented migrants, Missed appointments, Antiretroviral therapy, Self-transfer, Electronic patient management system.

#### Article History

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## 1. INTRODUCTION

### 1.1. Background

South Africa (SA) is home to diverse historical and contemporary population movements, predominantly associated with livelihood seeking [1]. Since the eradication of apartheid, migration patterns in SA have shifted, and it is a

destination for many migrants from African countries and other countries worldwide [2, 3]. Migration caused by political instability, socioeconomic disparities, and environmental events has become a global issue entailing major health challenges, particularly access to health services in destination countries [4 - 6].

Across Sub-Saharan Africa (SSA), China, and South East Asia, migrants are present with higher Human Immunodeficiency Virus (HIV) prevalence or greater HIV risk behaviours [7]. South Africa is the largest recipient of migrants

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from the Southern African Development Community (SADC) [1, 8]. The literature suggests that between three and four percent of South Africa's population are from sub-Saharan countries, with these individuals distributed across South Africa's nine provinces [1]. Some of the literature indicated that the various data sources estimate that two to three million foreign nationals are currently living in SA [9]. This number includes both documented and undocumented migrants, along with refugees and asylum seekers [9]. Other sources mentioned that the estimates of cross-border migration in SA vary widely; however, the national census data from 2011 suggest approximately 1.7 million migrants in the country [10, 11].

Also, many lower-skilled international migrants find a way to legalise their stay in SA, falling within the periphery of health and social welfare provision and relying on a survivalist livelihood within the informal economy [12]. International response to providing healthcare to non-citizens, particularly the undocumented, varies significantly from country to country [13]. Countries, such as Belgium, France, and the United Kingdom, extend HIV care to undocumented migrants, but other countries do not provide any services and even restrict healthcare access [13]. Of 48 responding countries in the WHO European Region, only 21 provide gratuitous Antiretroviral Therapy (ART) to undocumented migrants [13]. Similar practices identified in various studies indicate that other countries offer free treatment to undocumented migrants, including SA [12 - 15]. South Africa provides healthcare services regardless of the legality; therefore, undocumented migrants can access HIV treatment at any public health care facility [16]. South Africa responded to the 1996 Constitution which guarantees that all persons, including documented and undocumented immigrants, have access to the healthcare system, expansively defining the rights of immigrants and human rights violations [10, 17].

The literature suggests that the numbers of international migrants in SA requiring healthcare, including ARV, are relatively low [7, 13]. The limitation of this study was that there was no investigation to determine the number of migrants utilising healthcare services. However, the study identified a high prevalence of undocumented migrants accessing ART in the healthcare facilities of SA, and they formed a higher number of clients missing appointments. As a result, this study focused on the behaviour and socioeconomic factors of undocumented migrants resulting in their failure to keep to the appointment schedule for ART refills and follow-up. It is vital to ensure that decisions to reduce poor compliance to ART appointments amongst this population are informed by empirical support. Failing to keep an ART appointment is considered illegal health behaviour affecting the person's health and increasing the burden on the health services [18, 19].

## 2. METHODS

### 2.1. Overview

This paper was extracted from the first author's dissertation submitted in fulfillment of the requirements of a Doctoral of Philosophy in Public Health. That study aimed to develop a strategy to reduce the missing appointment among adult clients on ART.

### 2.2. Study Design

A cross-sectional, explorative, qualitative design was used in this study to understand the phenomenon and obtain an in-depth understanding of the study. The researcher used qualitative research to explore and understand the meaning of individuals or groups ascribed to social or human problems [20].

Purposive criterion sampling was used to identify undocumented migrants with strong migratory issues, such as not having identification numbers in the monitoring system but registered as 18 years of age and above according to their unconfirmed date of birth. This method of sampling helps to create a homogenous sample of participants who have experienced the phenomenon.

The study setting was also selected using a purposive sampling method. Two districts were selected based on geographical allocation and with a high volume of migrants utilising healthcare facilities. Moreover, these two districts were selected because they are directly sharing international borders with three countries, namely: Botswana, Zimbabwe and Mozambique, and Mpumalanga Province. The study was conducted in four facilities situated near the border post across these two areas.

The challenges to get participants for this study were anticipated due to their identity. The researcher planned to interview the available participants meeting the required criteria. Hence, there was no specific number to recruit. However, 24 undocumented migrants were identified for the interview. Participants who had missed more than four appointments were randomly identified from the Electronic Patient Management System (normally called the TIER.net system), and those who met the criteria were recruited. The researcher spent at least two to three weeks in each facility to contact these participants when they arrive to collect their repeat medication. Other arrangements were made with the facility staff members to recruit participants when they come in absentia of the researcher. Staff members connected the researcher with the participants telephonically to arrange for the interview.

Each participant signed a written consent form that explained their rights as participants, and these signed forms were collected, and each was assigned as a pseudonym. Although there is no standard for a minimum number of participants in qualitative research because its purpose is not to generalise, data saturation was reached in the sample of 17 undocumented migrants. No further recruitment was done for the interviews.

### 2.3. Data Collection

The researcher was trained in the qualitative approach before conducting the study. A semi-structured one-on-one interview with an interview protocol was used to collect information. The supervisor, co-supervisor, and independent coder expert reviewed this protocol. Any feedback received was implemented if necessary to ensure that the process provided the results.

To obtain the participants' perspectives, follow-up and

probing questions techniques were used to encouraged them to elaborate and clarify responses throughout the interview process. Semi-structured interviews provide opportunities for interviewees to raise additional issues that are important to them and allow the researcher to pursue interesting issues raised during the interviews [21]. The principal researcher conducted all interviews in a room provided at the healthcare facility, and each was recorded for accuracy. Data collection was completed over four months after no new information emerged to add to the understanding of the phenomenon. Data saturation was declared at that point.

#### 2.4. Data Analysis

Thematic data analysis is the most common form of analysis in qualitative research [22] and is used to analyse the data in this study. This method determines, examines, and records themes within the data collected. The formulated themes become patterns across data sets and describe the phenomenon associated with the study question [22]. Six phases to create meaningful patterns were conducted throughout the process of coding [20, 22]. Reading and re-reading material until the researcher is comfortable is crucial in this phase [20]. After each transcript was read twice to immerse the researchers in the data, key concepts were highlighted (Inductive coding). These phases are essential to familiarise the researchers with the generated data. Once these phases are completed, the researchers review the themes and provide definitions and names for those themes. A cyclical process was employed where the researchers carefully examined and re-examined the data during the analysis process until satisfied with the final themes [20, 22 - 26].

#### 2.5. Reliability and Validity

Reliability and validity were ensured through intercoder agreement, audio recording, triangulation, bracketing, and member checking.

#### 2.6. Measures to Ensure Trustworthiness

Three criteria, namely credibility, confirmability, and transferability, were used to ensure trustworthiness [27]. In order to ensure credibility, the principal researcher stayed in the field for four months as it was challenging to access the undocumented migrants visiting the facility for treatment refills, and the interview sessions extended to 40–50 minutes. Confirmability was observed by making provisions for data recording using a voice recorder and making field notes. Lastly, the purposive selection of the participants who met the inclusion criteria was considered to ensure transferability.

#### 2.7. Ethical Consideration

The ethical clearance for this study (SHS/17/PH/13/1603) was granted by the University of Venda Research Ethics Committee. The permission to collect data in the healthcare facilities was obtained from the Department of Health, Limpopo province, and in each district by the district executive manager. The aim of the study was explained to the participants and informed consent was obtained voluntarily. The participants were also informed that their information

might be used in publications or conference presentations and their identities will remain anonymous.

### 3. RESULTS

A total of 17 undocumented migrants participated in the study. Males constituted nine of the participants, with eight females aged 20-45 years. Four themes emerged, including (1) Self-transfer to other facilities without notification, (2) Medication hoarding and sharing behaviours (to prevent medication stock out while moving from one place to another), (3) Fear of xenophobic attacks, (4) Socioeconomic challenges.

#### 3.1. Self-Transfer to other Facilities Without Notification

The expanding ART coverage has increased the decentralisation of ART services to primary healthcare facilities, and clients can choose where they access ARV drugs. The study finds that the number of participants' transferring between ART-providing healthcare facilities increased substantially. Participants continued to self-transfer to another facility without notification for various reasons. This challenging situation was confirmed by this participant who mentioned that:

"I do not leave the facility internationally, but I got a phone call for a job in the evening. So, I left early in the morning without saying goodbye. When you arrive at the place, you find that it is a year contract. I located the nearest clinic and continue collecting treatment there." (P6, 33-year-old male)

The majority of participants mentioned that the main reason for leaving their countries was not merely to get ARV medication but for employment. That is why they find themselves moving from one place to another. They added by indicating that they do not find permanent jobs. Hence, they take advantage of any facility near their workplace.

"I have to leave Mpumalanga Province because my contract just ended abruptly. Then I started to look for another job. That is why I am moving points to points. I collect medication wherever I am at that time." (27-year-old male)

*One female participant mentioned that:* "I was staying with my husband, who succumbed to HIV, at his workplace. Then I vacate the area because I was not a worker on that farm and come here to stay with my sister. She is the one who introduced me to this facility." (P5, 43-year-old female)

#### 3.2. Medication Hoarding and Sharing Behaviours

The study found that some ART participants registered to several healthcare facilities because they want to accumulate medication to prevent running out while travelling from one place to another. This was identified during the interview with the participants when asked if they were not afraid to relapse to HIV-defining illness. The participants revealed that they never run out of stock. When asked how possible, some responses were the following:

"I am from M....., we are a group registered in plus or minus four facilities around this area. After three months, we arranged a taxi to come to SA for child grants and the collection of medications. Then went home. Just like that."

**(P2, 37-year-old female)**

“I am working piece jobs, so sometimes it is difficult to go to the clinic on a specific date. As a result, I sometimes run out of medication. So, what I have done, I registered myself to three facilities so that I get more than three-month supply....”

**(P15, 40-year-old female)**

“My partner sometimes refuses to go to the clinic for a follow-up visit. Hence, we share the treatment. I must make sure that I have enough stock for both of us. Sometimes you find that we receive a two-month supply....., that is why sometimes it took us a long time to go to the clinic on the given dates.” **(P6, 31-year-old female)**

Two participants revealed that they collect as much ARV stock as possible from various healthcare facilities so that they can send it to their family members who cannot access health care facilities at home.

“My mother and brother are also HIV positive, and the clinic is far away. Sometimes they do not find medication at the clinic. Hence, I am assisting them.” **(P7, 37-year-old female)**

**3.3. Fear of Xenophobic Attacks**

The study findings revealed that most migrant participants were not traceable because they provide false personal identity. The question is why they prefer to use a false identity? Many mentioned that they are the victims of xenophobic attacks. The participants stated that hiding their identity makes it easier for them to move and start a life somewhere new when they realise that they are no longer welcome in that area.

“I always hide my true identity because of xenophobia. When I realised that people start to dislike us, we move to the next village and register a new identity. When we go to the clinic, we start afresh and test positive. Then enrolled to programme afresh as J.... instead of B....” **(P14, 24-year-old male)**

“Mostly I use V.... surname claiming that I am V...., so that I can conform to the group. Foreigners are regarded as thieves and carriers of HIV diseases. Being a foreigner with HIV disease, the chances of being attacked are high. That is why even though I go to the clinic, I make sure that the people in the clinic are not the ones residing where I am staying. So, it possible that I go to the clinic several times without collecting treatment until I get a perfect opportunity.” **(P3, 29-year-old male)**

A probing question was asked if community members have ever attacked them. One participant responded as follow:

“No, not a physical attack, but a verbal attack. You find that when you are still in the queue at the clinic, other people will make nasty comments about foreigners. Mentioning that we are there to hoard medication to sell it or send it home. Mostly I don't go to the clinic on busy days, I prefer weekends.” **(P3, 29-year-old male)**

**3.4. Socioeconomic Challenges**

Most participants mentioned that the reason for leaving

their country was not merely for the HIV program but to seek employment. Some mentioned that they were HIV-negative when they came to SA. Since they did not have proper documentation, they had to accept low-skilled jobs. The majority of the working participants were working on the farms, and others were working for contractors. Some responses were as follows:

“I am afraid to request permission to go to the clinic because I might lose my job. Getting another job without proper documentation is difficult unless you know someone to advocate for you.” **(P9, 41 year-old-male)**

“Sometimes we receive the message in the morning that we must come with our belongings because we are going to work on a project somewhere. It is challenging for me because I do not have relatives or someone to send to the facility to collect on my behalf.” **(P10, 30-year-old male)**

Some participants mentioned that they had financial challenges, as other jobs were paying them lower wages. Furthermore, they indicated that they were not paid appropriately because the employer takes advantage of their being illegal migrants without documentation. Hence, most of the time, they work several jobs in order to meet their financial requirements. Some mentioned that they missed their clinic scheduled appointments while they were looking for better working conditions.

“If I want to have enough money for living and to send some home, I must work every day, Monday-to-Sunday.” **(P2, 27-year-old male)**

“During the weekdays, I am at work on the farm and during the weekend, I work domestically to boost my wage. Collecting medication sometimes becomes challenging unless I pretend to be sick.” **(P4, 31-year-old male)**

**4. DISCUSSION**

The study aimed to explore the behaviour and socioeconomic factors of undocumented migrants missing clinic appointments. The study findings demonstrated that clients are not necessarily missing their clinic appointments; the problem is that they transfer themselves to other facilities while looking for work without notifying the previous healthcare facility. Hence, the monitoring system in their previous healthcare facility identifies them as not attending, and or they are declared missing or lost to follow up in the worst-case scenario.

Literature suggests that most clients find it comfortable to access ART services close to home or their workplace, hence they self-transfer themselves [28]. It was established that accessing medication close to their homes or workplaces is an important way to retain clients in care [28 - 31]. Self-transferring has negative implications on the previous healthcare facility in terms of cost, resource allocation, and tracing. Clients should notify their facility one way or another about their relocation so that they can be recorded accordingly.

The study revealed that some clients fear that they might run out of medication while travelling from one place to another or if they are unable to take a day off from their work,

hence they accumulate medication from various healthcare facilities. Risk factors for ART discontinuation have not been explored extensively in this study. However, there is evidence that ART discontinuation results in drug resistance, diminishes the immunological benefit of treatment, and increases AIDS-related morbidity and mortality [32 - 35].

The discontinuation of ART is known to be a significant problem internationally. Research has shown that socio-demographic, behavioural, clinical, and institutional factors are high-ranking contributors to discontinuation [35]. Participants in this study hoard medication to avoid discontinuing treatment. The findings suggest that the participants are aware of the implication of defaulting from their ARV medications. Besides understanding the implications of treatment, the study revealed that the participants were collecting treatment for their family members who could not access healthcare facilities in their home country. The problem of borrowing and sharing medications among family members has been poorly recognised and never thoroughly investigated among the clients [36 - 38]. Literature suggests that it is common to share painkillers and other chronic medications, like hypertension and diabetic medications [37 - 39]. However, the sharing or borrowing of ARV treatment to family members who are sick has not been explored. A study conducted in Malawi revealed that guardians collect ART medication on behalf of their family members and sent it through truck and bus drivers to the migrants in SA, hence some clients do not go to healthcare facilities as scheduled [10]. Sharing of medication is risky behaviour that poses a life-threatening condition to the healthy individual who receives ARVs without being properly monitored [39 - 42].

Some of the participants in this study indicated that they were afraid to provide correct personal information when they access facilities because they did not want to be identified as foreign nationals. The participants mentioned that they are verbally attacked at the health facilities, particularly when the facility reports that they are running short of medication. As a result, clients miss clinic appointments. Literature shows that non-South African citizens are subjected to medical xenophobia in the attitudes and practices of healthcare professionals [43, 44]. Policies that promote cultural integration and understanding are essential to improve community health for all [45, 46].

The study found that financial challenges were the biggest problems for the study participants resulting in the failure to appear for the clinic appointments. They missed clinic appointments because of the fear of losing their jobs. Other participants had to extend the working hours to generate income in order to assist the families back home; consequently, the appointment date is overlooked. Most immigrants are faced with challenges of finding employment because they do not have legal documentation [46].

The provision of ART to undocumented migrant populations raises particular challenges with respect to ensuring adequate treatment support, adherence, and retention in care [47 - 50]. The result of this study would be particularly helpful to both healthcare providers and the Department of Health program managers because these insights about the

behaviours and socioeconomic factors displayed by undocumented migrants may be useful to improve the Electronic Patient Management System. The conclusion drawn from this study is that the current monitoring system in the healthcare facilities cannot identify if the client has collected medication somewhere or is self-transferred to other healthcare facilities.

## CONCLUSION

In conclusion, the study found that clients miss clinic appointments due to behavioural and socioeconomic factors. Clients self-transfer to other healthcare facilities without notification, whereas, others collect medication as many as possible while job hunting or avoiding time off from their respective workplace. The implication of the findings denotes that there is a need to improve the Electronic Patient Management System. Furthermore, more studies are needed to investigate how the monitoring system can be improved so that it can report clients' movements and how migrants without documents can be authentically registered in healthcare facilities.

## LIMITATION OF THIS STUDY

Although the findings contribute to a more comprehensive understanding of why undocumented migrants miss their clinic appointments, they cannot be generalised to all as this study included limited facilities of the Limpopo Province. Data saturation was reached in the sample of 17 undocumented migrants, hence, the information obtained cannot be generalised to all undocumented migrants. It is also crucial to note that the results of this study were self-reported, and some responses may be biased towards social desirability.

This study also does not provide evidence whether the undocumented migrants who participated in this study intended to miss clinic appointments. The participants in this study were mostly from Zimbabwe and Mozambique; it remains unknown whether the findings regarding the behaviour and socioeconomic factors of undocumented migrants missing clinic appointments would be observed in other similar groups from other countries.

## LIST OF ABBREVIATIONS

<b>ART</b>	= Antiretroviral therapy.
<b>ARV</b>	= Antiretroviral.
<b>HIV</b>	= Human immunodeficiency virus.
<b>SA</b>	= South Africa.
<b>SADC</b>	= Southern African Development Community.
<b>SSA</b>	= Sub-Saharan Africa.
<b>TIER.net</b>	= Three Interlinked Electronic Register network.

## AUTHORS' CONTRIBUTIONS

MPL participated in designing research protocol, collecting data, and drafting the manuscript. RTL participated in data analysis, verifying the drafted manuscript, and auditing the references.

## ETHICS APPROVAL AND CONSENT TO PARTICIPATION

The ethical clearance for this study was granted by the University of Venda Research Ethics Committee (Approval No. SHS/17/PH/13/1603). The permission to collect data in the healthcare facilities was obtained from the Department of Health, Limpopo Province, and each district by the district executive manager.

## HUMAN AND ANIMAL RIGHTS

No animals were used in this research. All human research procedures followed were in accordance with the ethical standards of the committee responsible for human experimentation (institutional and national), and with the Helsinki Declaration of 1975, as revised in 2013.

## CONSENT FOR PUBLICATION

All clients participated voluntarily and gave their informed consent.

## AVAILABILITY OF DATA AND MATERIALS

The datasets generated and/or analysed during the current study are available from the corresponding author [M.P.L.] on reasonable request.

## FUNDING

None.

## CONFLICT OF INTEREST

The authors declare no conflicts of interest, financial or otherwise.

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