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BEHIND THE REFUSAL: NURSES' EXPERIENCES IN CARING FOR HIV PATIENTS WHO DECLINE ANTIRETROVIRAL THERAPY

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ABSTRACT

People living with HIV who refuse antiretroviral therapy (ART) present unique challenges for nurses, who must balance respect for patient autonomy with the provision of quality care. These situations may lead to emotional stress, ethical dilemmas, and professional challenges, which can affect nurses' ability to provide optimal care. This study explored the experiences of registered nurses in selected hospitals in Region III, specifically in Bulacan and Pampanga, who cared for people living with HIV who refused ART. Using a qualitative descriptive design, eight nurses were purposively selected to participate in semi-structured interviews. Data were analyzed using Braun and Clarke's Thematic Analysis to identify significant statements and generate themes, including (1) Patient Readiness and Acceptance, (2) Barriers to ART Acceptance, (3) Nursing Strategies in ART Refusals, and (4) Strengthening HIV Care Systems. The study aimed to provide insights into nurses' experiences in HIV care and contribute to improved healthcare policies and more patient-centered strategies for managing treatment refusal. This study was conducted over a period of nine months, from September 2025 to May 2026.

Keywords: *HIV, antiretroviral therapy, ART refusal, autonomy, ethical dilemmas*

INTRODUCTION

Human Immunodeficiency Virus (HIV) continues to be one of the most pressing public health challenges around the world. By the end of 2022, approximately 39 million people were reported to be living with HIV, with sub-Saharan Africa carrying the greatest burden of cases (UNAIDS, 2023). Even though significant progress has been made in prevention and treatment, HIV remains a life-changing illness that demands long-term care and attention. Managing HIV requires not only medical treatment but also social and psychological support, since patients often face stigma and discrimination that may affect their willingness to seek care (Mahajan et al., 2008).

The development of antiretroviral therapy (ART) has been one of the greatest achievements in public health. ART makes it possible for people living with HIV to live longer, healthier lives by reducing the amount of virus in their bodies. It also prevents the virus from being transmitted to others, turning HIV from a fatal condition into a manageable chronic illness (World Health Organization [WHO], 2021). For this reason, ART is considered essential not only for individual survival but also for global efforts to control the epidemic. However, despite its benefits, not all patients are willing to start or continue with treatment.

Treatment refusal is influenced by several factors. Patients may fear the side effects of the medicines, worry about being judged by others, or believe that they did not need treatment because they “feel healthy” (Katz et al., 2015). In some communities, cultural and religious beliefs also play a role in discouraging acceptance of ART (Nhemachena et al., 2023). Refusing treatment may allow HIV to progress into Acquired Immunodeficiency Syndrome (AIDS), where the immune system becomes severely damaged and opportunistic infections can become life-threatening. Treatment refusal also increases the risk of transmitting the virus to others, making it not only a personal decision but also a public health issue.

The problem of ART refusal affects broader global goals. The UNAIDS 95–95–95 target aims for most people living with HIV to be diagnosed, treated, and virally suppressed. However, refusal and disengagement make this goal difficult to achieve (UNAIDS, 2023; Magura et al., 2025). The challenge goes beyond the availability of treatment and involves addressing the personal, social, and systemic barriers that keep people from starting or staying on ART. Understanding these barriers requires listening not only to patients but also to the healthcare providers who care for them every day.

Nurses play a central role in this context. As frontline providers, they are responsible not just for giving out medicines but also for educating patients, offering counseling, and providing emotional support. They are often the closest point of contact for people living with HIV, and their actions and attitudes can strongly influence patients’ decisions. When patients refuse ART, nurses must balance respect for patient autonomy with their duty to provide quality care and promote health. This creates ethical and emotional dilemmas that can be challenging to manage (Nhemachena et al., 2023).

Many nurses report experiencing both empathy and frustration when dealing with patients who decline treatment. On one hand, they understand the fears, struggles, and social pressures their patients face. On the other hand, they may feel discouraged when patients refuse care, especially when these refusals increase the nurses' workload and affect treatment outcomes. This mix of emotions reflects the difficult position nurses occupy in HIV care, where they must continuously navigate between compassion and professional responsibility (Nhemachena et al., 2023; Bedert, 2024).

The lived experiences of nurses show how ART refusal can affect their sense of professional identity. Some feel powerless when their patients continue to decline care despite repeated counseling and education. This can create emotional stress, since nurses dedicate their efforts to saving lives but are unable to change the patient's decision. Others try to focus on building trust and maintaining supportive relationships, believing that strong rapport may eventually encourage patients to accept treatment. These situations show how nurses' roles extend beyond medical tasks and into complex human interactions (Bedert, 2024; Nhemachena et al., 2023).

Ethical challenges are also common in nurses' experiences. They are trained to respect patients' rights and autonomy, yet they are also aware of the serious consequences of refusing ART. This dual responsibility often creates inner conflict. Nurses may struggle with feelings of guilt, worrying that they have not done enough to convince patients, while also recognizing that they cannot force anyone to take treatment. Such experiences emphasize the need for emotional resilience and strong ethical grounding in HIV care (Nhemachena et al., 2023).

Nurses' lived experiences also highlight the importance of institutional and peer support. When patients disengage from ART, the burden does not fall on one individual alone but on the entire healthcare system. Proper follow-up systems, supportive colleagues, and adequate training can help nurses cope with the stress of handling refusal. Without such support, they may feel isolated, overworked, and emotionally drained. This shows how organizational structures and healthcare policies play a role in shaping how nurses manage treatment refusal in practice (Bedert, 2024; Lowane & Lebese, 2022).

The experiences of nurses further reveal how ART refusal impacts their relationships with patients. Trust can be weakened when patients perceive nurses as too forceful or judgmental, but it can also be strengthened when nurses show understanding and patience. This balance between firmness and empathy is something nurses constantly work to maintain, as it affects not only the individual patient but also the quality of healthcare provided (Bedert, 2024; Nhemachena et al., 2023).

In the local setting, particularly in Bulacan and Pampanga, nurses are at the frontlines of HIV care within healthcare institutions. They often work with limited resources while addressing the social stigma that still surrounds HIV in the community. Their experiences with patients who decline ART highlight both the challenges of healthcare delivery and the resilience of nurses who continue to provide compassionate care despite

barriers. By sharing their perspectives, this study aims to give voice to their challenges and contribute knowledge that can improve health services.

This study explored the experiences of nurses caring for people living with HIV who refused ART. By focusing on their perspectives, the study shed light on the challenges they faced, the strategies they used, and the emotions they experienced. Their insights are important not only for improving patient care but also for shaping policies and practices that support both healthcare workers and patients. Understanding nurses' experiences may contribute to building stronger, more patient-centered HIV care systems that address the realities of treatment refusal while promoting better health outcomes for all.

Review of Related Literature

The issue of treatment refusal in HIV care has been widely discussed across different regions, showing that patients' decisions are shaped by social, cultural, and personal contexts. A scoping review in sub-Saharan Africa revealed that barriers to ART adherence included stigma, financial difficulties, long travel distances, and poor access to healthcare facilities (Magura et al., 2025). These barriers demonstrate that treatment refusal is not always a simple matter of choice but may result from combined pressures that prevent patients from engaging in consistent care. Nurses working in these environments face the challenge of addressing factors that extend beyond their clinical duties, making their role more complex. Their responsibilities may involve understanding the circumstances affecting patients' decisions and finding appropriate ways to provide support while maintaining respect for patient autonomy.

Stigma continues to be one of the strongest barriers to ART initiation and adherence. Patients who fear being judged or exposed may choose to refuse treatment, even when they understand the risks (Mahajan et al., 2008; Magura et al., 2025). For nurses, this reality emphasizes the importance of building trust and maintaining confidentiality. When patients feel accepted, respected, and safe, they may be more willing to remain in care and discuss their concerns about treatment. However, reducing stigma requires more than individual efforts; it also demands system-wide awareness, education, and public health initiatives. Nurses therefore have an important role in creating a supportive environment where patients can openly communicate without fear of discrimination.

Another important factor influencing ART refusal is the perception of health. Some patients believe that feeling physically well means they do not need treatment. Katz et al. (2015) reported that many South African patients refused ART because they considered themselves "too healthy," even though they were already medically eligible for treatment. Such perspectives highlight a disconnect between medical advice and patients' understanding of HIV as a condition that can progress without obvious symptoms. Nurses often need to provide counseling to explain that HIV can progress silently and that refusing treatment can result in severe health consequences. This educational role requires patience, effective communication, and an understanding of each patient's level

of readiness, especially when patients are reluctant to accept their diagnosis or the need for lifelong treatment (Katz et al., 2015).

The healthcare setting also plays a major role in whether patients accept and continue treatment. A study in South Africa showed that missed appointments were linked to systemic problems such as long waiting times, poor booking systems, and inadequate follow-up practices (Lowane & Lebese, 2022). Nurses working in such conditions not only provide direct patient care but also manage the frustration of patients who feel neglected or unsupported. These findings suggest that improving healthcare systems through better scheduling, shorter waiting times, and stronger follow-up and support structures can help address barriers to treatment. Without such improvements, nurses may continue to struggle with patients who become disengaged from care. This shows that treatment refusal and discontinuation cannot be addressed solely through patient education because healthcare systems themselves may contribute to difficulties in maintaining treatment.

Nurses themselves often describe their experiences with patients who refuse ART as emotionally demanding. A study in Europe found that HIV specialist nurses experience complex professional and emotional demands when supporting people living with HIV (Bedert, 2024). They may feel empathy for patients' struggles but also frustration when refusals lead to worsening conditions and increased workload. This dual burden shows that ART refusal does not only affect patients' health but also the well-being of healthcare providers. Nurses may invest considerable time in providing education, counseling, follow-up, and emotional support, yet they must still respect the patient's final decision. Understanding this emotional impact is essential for designing support programs that can help nurses manage the demands of HIV care while maintaining quality patient care.

Cultural and religious beliefs also strongly influence treatment decisions. In some cases, patients rely on faith healers, spiritual leaders, or herbal remedies instead of ART. Research from South Africa showed that nurses frequently encounter patients who believe HIV is a spiritual illness or that it can be cured through religious faith (Nhemachena et al., 2023). Such beliefs create difficult situations for nurses, who must respect cultural and religious values while stressing the importance of evidence-based medical treatment. The balance between cultural sensitivity and evidence-based care remains a key challenge in nursing practice, particularly in settings where traditional beliefs are deeply rooted. Nurses must communicate treatment information without immediately dismissing patients' beliefs, as doing so may damage trust and make patients less willing to engage in care (Nhemachena et al., 2023).

The quality of the nurse–patient relationship also affects whether patients remain in care. Studies highlight that when patients feel heard, respected, and supported, they are more willing to continue treatment. Nurses who practice open communication, empathy, and confidentiality can help reduce fears of stigma and encourage adherence (Bedert, 2024; Nhemachena et al., 2023). Conversely, negative interactions, such as judgmental attitudes or lack of support, may push patients away from treatment. These findings underline the importance of interpersonal skills in nursing practice, especially

when dealing with sensitive conditions such as HIV. Establishing a trusting relationship allows nurses to understand patients' concerns and identify possible reasons behind treatment refusal. Rather than focusing only on whether a patient accepts ART, nurses may need to consider the patient's readiness, experiences, fears, and circumstances.

Loss to follow-up remains a major concern for ART programs. Patients who initially accept treatment may later stop attending clinic visits because of financial struggles, relocation, stigma, or misinformation about side effects. A study in Ghana found that patients were often lost to follow-up because of wrong addresses, poor communication networks, geographical relocation, and lack of transportation (Kogi et al., 2024). Nurses in these cases often bear the responsibility of tracing patients and encouraging them to re-engage with care. This task requires additional effort and resources, making their role even more demanding in the context of HIV treatment programs. The responsibility of maintaining patient engagement therefore extends beyond the initial provision of ART and requires continuous communication and follow-up (Kogi et al., 2024).

At the same time, nurses face ethical dilemmas when patients refuse treatment. Respecting patient autonomy means acknowledging their right to refuse ART, but this may conflict with the professional duty to promote health and prevent harm. According to Nhemachena et al. (2023), healthcare workers in South Africa expressed both empathy and anger toward patients who disengaged, as refusals not only risked the patients' health but also created additional strain on the healthcare system. These dilemmas highlight the need for ethical guidance and institutional support to help nurses navigate situations where personal values and professional duties may conflict. Nurses must provide accurate information, ensure that patients understand the possible consequences of their decisions, and continue to offer appropriate care without forcing treatment.

The literature also demonstrates that nurses' responsibilities in HIV treatment refusal extend beyond traditional medical tasks. They serve as educators, counselors, advocates, and sources of emotional support for patients. Their experiences show that effective HIV care requires patience, communication, cultural sensitivity, and the ability to maintain professional relationships despite difficult situations. At the same time, nurses require support from healthcare institutions to manage the emotional and practical demands associated with treatment refusal. Adequate training, supportive colleagues, effective follow-up systems, and clear policies can help nurses respond more effectively to patients who refuse or discontinue ART (Bedert, 2024; Kogi et al., 2024; Nhemachena et al., 2023).

Overall, the literature shows that ART refusal is a complex issue that affects both patients and nurses. For patients, refusal is often shaped by stigma, misconceptions, cultural and religious beliefs, concerns about treatment, and systemic barriers (Katz et al., 2015; Magura et al., 2025; Nhemachena et al., 2023). For nurses, it brings emotional stress, ethical conflicts, additional responsibilities, and challenges in maintaining therapeutic relationships (Bedert, 2024; Nhemachena et al., 2023). Despite these challenges, nurses continue to serve as a bridge between patients and the healthcare system by providing education, counseling, follow-up, and emotional support. Their role

is particularly important because treatment decisions are influenced not only by medical information but also by the patient's personal experiences and social environment.

Research Questions

HIV patients who refuse antiretroviral therapy (ART) present unique challenges for nurses, who must balance patient autonomy with quality care. While research often focuses on patient adherence, little is known about the experiences of nurses in these situations.

This study explored the lived experiences of nurses in caring for HIV patients who refused antiretroviral therapy. Specifically, it answered the following questions:

1. What challenges do nurses encounter when providing care to people living with HIV who refuse ART?
2. How do nurses manage the ethical and emotional dilemmas that arise from treatment refusal?
3. What strategies do nurses use to support and communicate with people living with HIV who decline ART?
4. In what ways can nurses' experiences contribute to improving care and support systems for HIV management?

METHODOLOGY

This study used a qualitative descriptive research design to explore the experiences of nurses caring for HIV patients who refused antiretroviral therapy (ART). A qualitative descriptive approach was appropriate because it aimed to describe events and experiences in the most direct and simple form, staying close to the participants' actual words and perspectives (Sandelowski, 2000). This design fit the study since the goal was to understand how nurses faced the challenges, emotions, and responsibilities that came with caring for patients who refused ART.

The study used a non-probability sampling method, specifically purposive sampling. This method allowed the researchers to select participants who met the required criteria and had direct experience related to the topic (Creswell & Creswell, 2018). By selecting nurses who had handled cases of ART refusal, the researchers were able to gather relevant and meaningful information that helped deepen the understanding of the study.

Eight registered nurses were included in the study. This number was considered sufficient to provide a variety of experiences and helped the researchers understand the common challenges faced by nurses caring for HIV patients who refused ART. No additional participants were included since data saturation had already been reached, meaning no new ideas or information were emerging from the interviews. Through these

shared experiences, the study reflected the real situation of HIV care in Bulacan and Pampanga and highlighted the important role of nurses in managing treatment refusal.

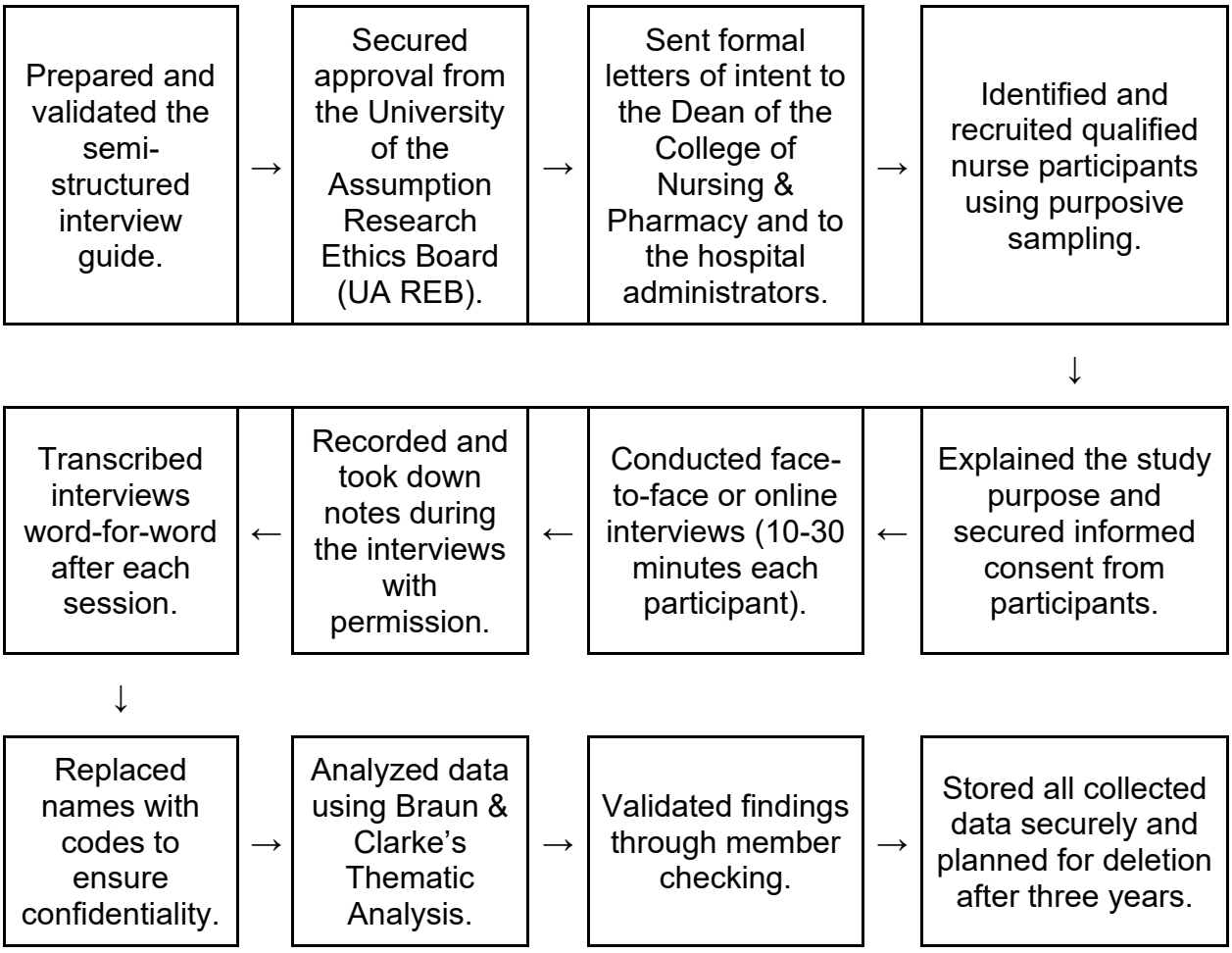


Figure 1. Data Gathering Flowchart

The data-gathering process began with the preparation of a semi-structured interview guide, which was the main tool for collecting information about the experiences of nurses caring for HIV patients who refused antiretroviral therapy (ART). After the interview guide was completed and validated, the researchers secured approval from the University of the Assumption Research Ethics Board (UA REB) to ensure that all ethical standards were followed. A formal request letter was then sent to the Dean of the College of Nursing and Pharmacy and to hospital administrators in Pampanga to ask for permission to conduct the study and identify qualified nurse participants.

Once approval was granted, purposive sampling was used to select registered nurses who had direct experience in caring for HIV patients who refused ART. The researchers reached out to these nurses personally through text messages, phone calls, and formal letters sent via email. They clearly explained the purpose of the study, the voluntary nature of participation, and the measures taken to protect their privacy. Each

participant was given an informed consent form before the interview to ensure that they fully understood their rights, including the option to stop or withdraw from the study at any time.

Interviews were conducted face-to-face in a private area within hospitals in Pampanga, while interviews in Bulacan were conducted through an online platform. Before starting, the researchers introduced themselves, gave a short orientation about the study and the interview process. Each interview lasted around 10 to 30 minutes and was audio-recorded with the participant's permission to ensure accurate reporting. The researchers also took brief notes during the conversation.

After all interviews were completed, the audio recordings were transferred to a secure digital folder and transcribed word-for-word. All identifying details such as names and personal information were removed and replaced with codes to protect confidentiality. The transcribed data were then analyzed using Braun and Clarke's Thematic Analysis. This process included becoming familiar with the data, generating initial codes, grouping the codes into patterns, identifying themes, reviewing and refining the themes, and writing the final.

All collected information was kept confidential and stored securely in line with the Data Privacy Act of 2012. The data will be stored for three years and will then be permanently deleted or destroyed.

Research Instrument

The main tool for data collection was a semi-structured interview guide. It contained open-ended questions that encouraged nurses to share their thoughts and experiences freely. This method was effective because it helped the researchers gather detailed and honest responses while still keeping the focus (DeJonckheere & Vaughn, 2019). The interview guide was divided into three (3) parts: demographic profile, interview proper, and post-interview questions.

Part 1: Demographic Profile: This part gathered the participants' background information, including name, age, sex, years as a registered nurse, years of experience as an HIV nurse, and their current treatment hub and position.

Part 2: Interview Proper: This part consisted of open-ended questions focused on the nurses' experiences in caring for HIV patients who declined ART. It explored their daily experiences, challenges encountered, coping mechanisms, and insights for improving HIV care and support systems.

Part 3: Post-Interview Questions: This part included closing questions that allowed participants to share additional experiences and suggestions for improving support for nurses handling similar cases.

To ensure the validity, reliability, and appropriateness of the interview questions, the interview guide underwent pilot testing and was reviewed by a panel of three experts,

including two registered nurses with master's degrees who had attended HIV-related seminars and one psychometrician. Additionally, the Filipino-translated questions were reviewed by a Filipino teacher to ensure clarity, cultural relevance, appropriateness, and alignment with the objectives of the study.

Data Analysis

This study followed the six steps of Braun and Clarke's Thematic Analysis:

1. Familiarized with the data – read the interview transcripts
2. Generated initial codes – marked important words, ideas, or statements
3. Searched for themes – grouped similar codes together
4. Reviewed themes – checked if the themes match the data
5. Defined and named themes – explained what each theme means
6. Produced the report – wrote clearly based on the themes

The study employed Braun and Clarke's Thematic Analysis to examine the narratives of nurses caring for HIV patients who refused antiretroviral therapy (ART). This method provided a systematic yet flexible approach in identifying patterns of meaning across the dataset. The analysis began with repeated reading of the interview transcripts to allow the researchers to fully immerse themselves in the nurses' accounts and gain a thorough understanding of their experiences.

After familiarization, the researchers generated initial codes by marking and highlighting significant statements, emotional expressions, and notable insights related to the phenomenon. These codes were then organized and clustered to develop potential themes, which represented the broader ideas that captured the essence of the nurses' experiences. The themes were reviewed, refined, and clearly defined to ensure that they accurately reflected the data and remained faithful to the participants' perspectives.

Once the themes were finalized, the researchers crafted a coherent and meaningful presentation of the findings, showing how the themes connected and what they revealed about nurses' challenges, ethical dilemmas, communication efforts, and coping strategies. All data were anonymized and stored securely in accordance with ethical guidelines to uphold confidentiality and protect participant privacy.

Scope and Limitations

This study was limited to exploring the experiences of registered nurses in Bulacan and Pampanga caring for HIV patients who refuse antiretroviral therapy (ART). It focused on the challenges, ethical dilemmas, and strategies nurses faced and applied in these situations. Other healthcare professionals, such as doctors, counselors, or social workers, were not included, since the study centers on the nursing perspective. The findings were based only on the experiences of a selected group of nurses in Bulacan and Pampanga, and may not represent the views of all nurses in other areas. Despite these limitations,

the study provided important insights that can strengthen nursing practices and contribute to improved HIV care.

RESULTS

The study explored the experiences of nurses in caring for people living with HIV who decline Antiretroviral Therapy (ART). A total of eight nurse participants from two HIV treatment hubs in the Central Luzon - Region III were included in the study. All participants were registered nurses with varying years of experience in HIV care, ranging from 3 to 14 years, and the participants held different positions such as HACT Nurses, Nurse II, Nurse III, Nurse Supervisors, and Hub Managers. This shows that the sample included both frontline nurses and those in leadership or administrative roles in HIV treatment services. Regarding age, most participants were within the late 30s to early 40s, ranging from 37 to 41 years old. In addition, both male and female nurses were represented in the study, allowing for a balanced view of experiences across sex. Furthermore, the participants were assigned to different HIV treatment hubs located in Bulacan and Pampanga. These settings included both provincial and semi-urban areas, which provided varied experiences in terms of patient access, follow-up systems, and healthcare delivery.

Table 1: Demographic Data

Parti-cipant ID	Age	Sex	Years as RN	Years as HIV Nurse	Treatment Hub (Province)	Position
P1	38	M	18	11	Villa Esperanza (Bulacan)	HACT Nurse I
P2	38	M	16	14	Bahay Lingad (Pampanga)	HACT Nurse II
P3	38	F	18	7	Gintong Kanlungan (Bulacan)	Hub Manager
Parti-cipant ID	**Age**	**Sex**	**Years as RN**	**Years as HIV Nurse**	**Treatment Hub (Province)**	**Position**
P4	37	F	17	11	Bale Angeleño (Pampanga)	HACT Nurse III
P5	41	F	20	11	Bale Angeleño (Pampanga)	HACT Nurse III

P6	40	M	19	3	HMN Care Center (Bulacan)	Hub Manager
P7	39	M	3	3	YCAP Community Center (Pampanga)	Nurse Supervisor
P8	38	F	5	5	ABE LoveYourself (Pampanga)	Hub Manager

Through thematic analysis of in-depth interview data, four main themes emerged from the experiences of nurses caring for people living with HIV who decline Antiretroviral Therapy (ART). These themes reflected the different factors that affect treatment refusal and care. These include: (1) Patient Readiness and Acceptance, (2) Barriers to ART Acceptance, (3) Nursing Strategies in ART Refusals, and (4) Strengthening HIV Care Systems. Together, these themes answered the study's main question on the experiences of nurses in caring for people living with HIV who decline ART *(see Table 2 for supporting data and theme development).*

Table 2: Data Analysis

INTERVIEW EXTRACTS	GROUPED INITIAL THEMES	REVIEWED THEMES
"It is hard to force treatment when the patient is not ready." (P1) "We give them time to think and accept their situation." (P1) "Most of them are still in shock and not yet accepting their result." (P2) "Even after many counseling sessions, some patients are still in denial." (P3) "Some are in denial about their HIV status." (P5) "Many patients are still in denial and cannot accept their diagnosis." (P8)	**Difficulty in Acceptance** ● Denial of HIV diagnosis (P2, P3, P5, P8) ● Shock after positive result (P2) ● Emotional burden after diagnosis (P3, P8) ● Delayed treatment initiation (P1, P6) ● Temporary refusal of ART (P3, P6) ● Stopping treatment after feeling better (P5, P7) ● Misunderstanding recovery as cure (P7)	THEME 1: **Patient Readiness and Acceptance** SUBTHEMES: 1.1 Difficulty in Acceptance 1.2 Social Fear, Stigma and Emotional Distress

"They only stop treatment temporarily." (P6) "Some patients stop treatment after feeling better." (P5) "When symptoms disappear, they think they are already fine." (P7) "They refuse treatment and want to wait before starting." (P3)		
"Stigma is also a big reason why they refuse treatment." (P3) "Some patients do not want their family to know their HIV status." (P3) "Fear of discrimination makes them refuse treatment." (P8) "Patients often see HIV as a stigma or something shameful." (P8) "Some worry about losing their job or being judged if people find out their status." (P8)	**Social Fear, Stigma and Emotional Distress** ● Fear of discrimination (P3, P5, P8) ● Fear of HIV status disclosure (P3, P5) ● Confidentiality concerns (P3, P8) ● Stigma and shame (P5, P8) ● Emotional distress and anxiety (P3, P8) ● Fear of judgment (P8)	

INTERVIEW EXTRACTS	GROUPED INITIAL THEMES	REVIEWED THEMES
"Some believe supplements or vitamins are enough." (P7) "Some patients feel fine and have no symptoms, so they think they are okay." (P4) "Some patients are still in denial because they feel fine." (P2) "Some refuse because treatment is lifelong." (P5) "Some get tired of taking medicine daily." (P7) "Some stop treatment after feeling better." (P7)	**Misconceptions and Treatment Burden** ● Supplements as alternative cure belief (P7) ● Asymptomatic equals no treatment needed (P2, P4) ● Misunderstanding HIV severity (P2, P7) ● Fear of lifelong medication (P5) ● Treatment fatigue (P7) ● Stopping treatment after improvement (P7)	THEME 2: **Barriers to ART Acceptance** SUBTHEMES: 2.1 Misconceptions and Treatment Burden 2.2 Practical, Access and Follow-up Barrier
"Distance and transportation are also problems." (P4, P5) "Some patients go back to their province or become unreachable." (P5, P7) "Some patients cancel appointments repeatedly." (P8) "Some are not properly referred after testing." (P4) "Some patients change numbers or become unreachable." (P7)	**Practical, Access and Follow-up Barriers** ● Transportation barriers (P4, P5) ● Distance from treatment facilities (P4, P5) ● Missed appointments (P4, P8) ● Relocation to province (P5, P7) ● Loss of contact / unreachable patients (P2, P5, P7, P8) ● Work and schedule conflicts (P5, P8) ● Poor referral linkage (P4)	

INTERVIEW EXTRACTS	GROUPED INITIAL THEMES	REVIEWED THEMES
"We give them time before starting treatment." (P1) "We repeat counseling many times." (P7, P8) "We explain viral load so they understand." (P7) "We allow family or partners during consultation." (P6) "We keep communication open until they are ready." (P8)	**Therapeutic Communication and Patient-Centered Counseling** ● Repeated counseling sessions (P1, P7, P8) ● Clear explanation of HIV and ART (P1, P7, P8) ● Emotional support provision (P1, P3, P8) ● Respect for patient autonomy (P1, P2, P8) ● Non-coercive approach (P1, P8) ● Family or partner involvement (P5, P6) ● Trust-building with patients (P3, P8) ● Explanation of lab (P7)	THEME 3: **Nursing Strategies in ART Refusals** SUBTHEMES: 3.1 Therapeutic Communication and Patient-Centered Counseling 3.2 Continuous Monitoring and Support System
"We follow up patients who do not return." (P2, P4, P7, P8) "We contact patients through phone or social media." (P7) "We coordinate with NGOs and barangay health workers." (P2, P5) "We do monthly monitoring." (P4)	**Continuous Monitoring and Support Systems** ● Follow-up calls and messages (P2, P4, P7, P8) ● Case management tracking (P2, P4) ● NGO coordination (P2) ● Barangay health worker tracing (P5) ● City health office support (P5) ● Social media tracing (P7) ● Monthly monitoring system (P4)	

INTERVIEW EXTRACTS	GROUPED INITIAL THEMES	REVIEWED THEMES
"We need empathy and understanding." (P6) "We should never judge patients based on HIV status." (P8) "Trust between patient and healthcare workers is important." (P3) "Patients should feel respected and supported." (P8) "We should not make patients feel alone." (P7)	**Compassionate and Non-Judgmental Nursing Care** ● Trust-building in care (P3, P8) ● Empathy and compassion (P6, P7, P8) ● Non-judgmental attitude (P8) ● Emotional support provision (P6, P7) ● Patience in patient care (P7) ● Respectful treatment (P8) ● Strong nurse-patient relationship (P3, P7)	THEME 4: **Strengthening HIV Care Systems** SUBTHEMES: 4.1 Compassionate and Non-Judgmental Nursing Care 4.2 Improving Support Networks and HIV Advocacy
"Family support helps patients continue treatment." (P5) "Acceptance and family support are very important." (P5) "Advocacy requires patience and compassion." (P7) "We should not make patients feel alone." (P7)	**Improving Support Networks and HIV Advocacy** ● Family support importance (P5) ● Stigma reduction efforts (P8) ● Peer support systems (P7) ● Community awareness programs (P8) ● Continuity of care systems (P5, P7) ● HIV advocacy initiatives (P7)	

I. Patient Readiness and Acceptance

This theme explained that nurses viewed patient readiness as an important first step before starting Antiretroviral Therapy (ART). Many patients cannot immediately accept their diagnosis, so treatment was often delayed. Nurses shared that acceptance takes time, and emotional readiness was needed before patients could fully commit to treatment. Because of this, nurses focused on counseling and allowed patients to decide when they are ready.

1.1 Difficulty in Acceptance

This subtheme showed that many patients struggled with accepting their HIV diagnosis. Some were shocked after learning their result, while others remained in denial even after counseling. Nurses also noted that some patients delay or temporarily stop treatment once they feel better, thinking they are already fine. This showed that acceptance of diagnosis is a major step before treatment adherence.

> (P2) “Most of them are still in shock and not yet accepting their result.”
> (P3) “Even after many counseling sessions, some patients are still in denial.”
> (P1) “It is hard to force treatment when the patient is not ready.”
> (P7) “When symptoms disappear, they think they are already fine.”

These responses showed that emotional readiness and acceptance strongly affected the decision to start and continue ART.

1.2 Social Fear, Stigma, and Emotional Distress

This subtheme highlighted how social judgment and emotional burden affect treatment decisions. Patients often fear discrimination, stigma, and disclosure of their HIV status to others. Because of this, they experienced anxiety and emotional distress, which affected their willingness to start or continue treatment.

> (P3) “Some patients do not want their family to know their HIV status.”
> (P8) “Fear of discrimination makes them refuse treatment.”
> (P5) “There is a high level of stigma.”

These findings showed that fear of social judgment and stigma are strong barriers that affect patient acceptance and treatment engagement.

II. Barriers to ART Acceptance

This theme explained the different reasons why patients had difficulty starting or continuing Antiretroviral Therapy (ART). Nurses shared that refusal was not only about emotions, but also due to misunderstandings about HIV and real-life challenges

such as access and follow-up issues. These barriers affected treatment consistency even when services were available.

2.1 Misconceptions and Treatment Burden

This subtheme showed that some patients refused or delayed treatment because of wrong beliefs and fear about HIV and ART. Some think they do not need treatment because they feel fine or have no symptoms. Others believed that supplements or vitamins were enough. Nurses also noted that some patients stop treatment once they feel better or feel tired of taking lifelong medication.

> (P7) "Some believe supplements or vitamins are enough."
> (P2) "Some patients are still in denial because they feel fine."
> (P5) "Some refuse because treatment is lifelong."
> (P7) "Some get tired of taking medicine daily."

These responses showed that misunderstanding and treatment fatigue affect patient decisions and adherence to ART.

2.2 Practical, Access, and Follow-up Barriers

This subtheme highlighted real-life difficulties that prevented patients from continuing treatment. Nurses shared that some patients missed appointments, moved to other places, or became unreachable. Others faced problems with transportation, distance, or work schedules. Even when treatment is free, these practical issues still affect access and follow-up.

> (P4) "Distance and transportation are also problems."
> (P5) "Some patients go back to their province or become unreachable."
> (P8) "Some patients cancel appointments repeatedly."

These findings showed that structural and logistical problems also contribute to treatment interruption and loss to follow-up.

III. Nursing Strategies in ART Refusals

This theme explained how nurses responded to patients who delayed or refused Antiretroviral Therapy (ART). Nurses emphasized that their role focused on communication, support, and continuous follow-up rather than forcing treatment. They used different strategies to help patients understand their condition and guide them toward readiness for treatment.

3.1 Therapeutic Communication and Patient-Centered Counseling

This subtheme showed that nurses relied heavily on counseling, emotional support, and clear communication to help patients understand HIV and ART. They repeated explanations when needed and allowed patients time to decide. Nurses also involve family or partners when appropriate to strengthen understanding and support.

(P7) "We repeat counseling many times."
(P8) "We keep communication open until they are ready."
(P1) "We give them time before starting treatment."
(P6) "We allow family or partners during consultation."

These responses showed that continuous communication and patient-centered care help improve understanding and readiness for treatment.

3.2 Continuous Monitoring and Support Systems

This subtheme highlighted the importance of follow-up and coordination in patient care. Nurses regularly contacted patients who missed appointments and worked with other support systems like NGOs and community health workers. They also use different communication channels to reach patients who are lost to follow-up.

(P2) "We follow up patients who do not return."
(P4) "We do monthly case analysis & create strategies to bring them back."
(P5) "We coordinate with NGOs and barangay health workers."
(P7) "We contact patients through phone or social media."

These findings show that continuous monitoring and coordinated support are important in maintaining patient engagement in HIV care.

IV. Strengthening HIV Care Systems

This theme explained how nurses viewed the overall improvement of HIV care through better relationships, support systems, and advocacy. Nurses emphasized that effective HIV care is not only about treatment delivery, but also about how patients are treated emotionally and socially. Building trust and strong support systems helped improve treatment acceptance and continuity.

4.1 Compassionate and Non-Judgmental Nursing Care

This subtheme showed that nurses believed compassion, empathy, and non-judgmental care are essential in HIV management. Patients are more likely to trust healthcare workers when they feel respected and supported.

Nurses also emphasized patience, understanding, and emotional sensitivity when dealing with patients who are in denial or struggling emotionally.

(P8) "We should never judge patients based on HIV status."
(P3) "Trust between patient and healthcare workers is important."
(P6) "We need empathy and understanding."
(P7) "We should not make patients feel alone."

These responses showed that respectful and compassionate care strengthens patient trust and improves engagement in treatment.

4.2 Improving Support Networks and HIV Advocacy

This subtheme highlighted the importance of family involvement, community awareness, and support systems in HIV care. Nurses explained that patients are more likely to continue treatment when they have strong family support and access to community resources. Advocacy programs and peer support also helped reduce stigma and encourage treatment adherence.

(P5) "Family support helps patients continue treatment."
(P5) "Acceptance and family support are very important."
(P8) "Stigma reduction is important."
(P7) "Advocacy requires patience and compassion."

These findings showed that support networks and continuous advocacy played a key role in improving HIV treatment outcomes, reducing refusal or loss to follow-up.

DISCUSSION

This study explored the experiences of nurses in caring for people living with HIV (PLHIV) who decline Antiretroviral Therapy (ART) through semi-structured interviews with eight HIV nurses from different treatment hubs in Pampanga and Bulacan. Four central themes emerged: (1) Patient Readiness and Acceptance, (2) Barriers to ART Acceptance, (3) Nursing Strategies in ART Refusals, and (4) Strengthening HIV Care Systems. Participants described how treatment refusal is often not a direct rejection of ART, but a result of denial, emotional distress, stigma, misconceptions, practical barriers, and lack of readiness. Nurses emphasized that counseling, trust-building, empathy, and continuous follow-up are important in helping patients move toward treatment acceptance.

These findings indicate that ART refusal is a complex process influenced by both personal and social factors rather than simple non-compliance. Patients often need time to emotionally process their diagnosis before they can begin lifelong treatment. This supports the findings of Dhir et al. (2025), who found that HIV-related stigma strongly

affects ART uptake and adherence, particularly when patients fear judgment and discrimination. Their systematic review showed that stigma reduction interventions improve engagement in HIV care and treatment adherence. Similarly, Perger and Davtyan (2025) reported that stigma remains one of the strongest predictors of poor ART adherence and disengagement from care among young adults living with HIV. These findings support the present study's observation that acceptance and readiness are central to treatment initiation.

Theme 1 focused on Patient Readiness and Acceptance. Many participants shared that patients often remain in shock, denial, or emotional distress after diagnosis, making them unprepared to begin ART immediately. Some patients delayed treatment because they still could not accept their HIV status, while others stopped medication after temporary symptom improvement because they believed they were already well. This supports the study of Adesuyi et al. (2025), which found that recently diagnosed PLHIV commonly experience denial, fear, and anxiety that negatively affect medication adherence. Their study also emphasized that resilience and emotional support improve treatment continuation. Likewise, Nawfal et al. (2024) found that stigma and fear of disclosure significantly reduce retention in care and ART adherence, especially among women living with HIV. These findings support the present study's result that emotional readiness must come before treatment commitment.

Social fear, stigma, and emotional distress also strongly affected patient decisions. Many nurses shared that patients feared family rejection, workplace discrimination, and exposure of their HIV status. Some patients avoided treatment because they did not want others to know about their diagnosis. This is supported by Okello et al. (2025), who found that perceived stigma, shame, and fear of being recognized in HIV clinics hindered patients' engagement in HIV care. Their study also highlighted how confidentiality concerns and fear of being identified in treatment facilities affected clinic attendance and engagement in ART. Similarly, Vaughan and Költő (2024) explained that stigma within healthcare settings increases health avoidance behavior and weakens treatment adherence. This confirms the importance of confidentiality and trust in HIV care.

Theme 2 discussed Barriers to ART Acceptance. Nurses reported that misconceptions about HIV and ART strongly contributed to treatment refusal. Some patients believed supplements or vitamins were enough, while others thought they no longer needed ART because they felt physically well. Fear of side effects and lifelong medication also created treatment fatigue. This is consistent with Apuulison et al. (2025), who found that fear of lifelong medication, side effects, and treatment fatigue were major barriers to ART adherence among female sex workers. Their study showed that patients often stopped treatment once symptoms improved, believing they were already healthy. This directly supports the experiences shared by participants in the present study.

Practical barriers such as transportation costs, distance from treatment hubs, work schedules, and relocation also made follow-up difficult. Even when treatment was free, patients still struggled to return for consultations and medication refills. Loss to follow-up became common, especially among outreach patients who changed numbers or became

unreachable. This supports the findings of Okello et al. (2025), where case management and personalized follow-up improved clinic linkage and ART retention by addressing logistical barriers such as transportation and appointment access. Their findings suggest that refusal is often influenced by structural barriers rather than unwillingness alone.

Theme 3 focused on Nursing Strategies in ART Refusals. Nurses emphasized therapeutic communication and patient-centered counseling as their main approach. Rather than forcing treatment, they listened, reassured, repeated explanations, and gave patients time to decide. Some nurses also involved family members or partners during consultations to improve understanding and emotional support. This aligns with Dhir et al. (2025), who reported that counseling-based stigma reduction strategies significantly improve ART initiation and adherence. Their review showed that patient-centered communication helps reduce fear and improves readiness for treatment. Likewise, He et al. (2026) found that improving HIV knowledge among nurses reduces stigma and strengthens supportive care behaviors, which improves patient trust and communication.

Continuous monitoring and support systems were also important strategies. Nurses described follow-up calls, reminders, online communication, peer support, and coordination with NGOs, Barangay Health Workers, and City Health Offices. These systems helped trace patients who were lost to follow-up and maintained emotional connection without forcing treatment. This is supported by Okello et al. (2025), where case management and regular follow-up significantly improved HIV clinic attendance and ART adherence. Their study emphasized that gentle, consistent communication helps patients feel supported rather than pressured.

Theme 4 highlighted Strengthening HIV Care Systems. Nurses emphasized that compassionate and non-judgmental care improves patient trust and treatment engagement. They believed that empathy, patience, and emotional sensitivity are necessary because many patients are already vulnerable and afraid. Patients are more likely to continue treatment when they feel safe and respected. This supports Jordans et al. (2024), who found that institutional and individual stigma within healthcare settings negatively affects trust and treatment adherence. Their study emphasized that removing judgment and bias from healthcare delivery improves patient cooperation. Similarly, Vaughan and Költő (2024) noted that healthcare provider attitudes strongly influence retention in HIV care.

Improving support networks and HIV advocacy was also seen as essential. Nurses explained that family support, peer groups, referrals, and community education help reduce stigma and encourage treatment continuation. Patients who receive emotional and practical support from family are more likely to remain in care. This supports Nawfal et al. (2024), who found that disclosure and supportive family relationships improve retention in HIV care. Strong advocacy programs also help normalize HIV treatment and reduce discrimination. Dhir et al. (2025) further emphasized that community-based stigma reduction strengthens ART uptake and improves long-term adherence.

Overall, this study confirmed that ART refusal is rarely a simple refusal of medication. It is often connected to emotional readiness, stigma, practical barriers, and the quality of nurse-patient relationships. The findings showed that nurses play a major role not only in treatment delivery but also in emotional support, advocacy, and trust-building. Strengthening compassionate care systems and support networks remains essential in improving ART acceptance and long-term HIV management.

Conclusions

This study highlighted the different experiences of nurses caring for people living with HIV who refused antiretroviral therapy (ART). It showed that patient readiness, acceptance, and trust are very important before starting treatment. Many patients experienced denial, fear, stigma, and emotional distress, which made them delay or refuse treatment. Some also had wrong beliefs about HIV and ART, felt tired of taking lifelong medication, or faced problems such as transportation, missed appointments, and loss to follow-up.

The findings showed that nurses played an important role in helping patients understand their condition through good communication, repeated counseling, emotional support, and continuous follow-up. Nurses also respected patient autonomy by not forcing treatment and instead giving patients enough time to accept their diagnosis and become ready for ART. Compassion, patience, and non-judgmental care help build trust between nurses and patients.

Although the study was limited to a small group of nurses from Bulacan and Pampanga, it showed the need for better patient-centered HIV care. Improving counseling, follow-up systems, family support, community awareness, and stigma reduction can help patients stay engaged in treatment. Despite its limitations, the study provided useful insights and supports the need for stronger healthcare strategies to improve ART adherence and overall HIV care management.

Recommendations

1. For Nurses:

Nurses should continue to strengthen their skills in HIV counseling, therapeutic communication, and emotional support to better assist patients who refuse antiretroviral therapy (ART). Since many patients experience fear, denial, and emotional distress, nurses must respond with patience, empathy, and non-judgmental care. In this way, trust can be built, and patients may become more open and ready to begin treatment.

2. For Hospitals and HIV Treatment Hubs:

Hospitals and HIV treatment hubs should improve their follow-up systems to reduce missed appointments and maintain regular patient monitoring. Since some patients become unreachable or stop returning for treatment, stronger coordination and

continuous communication are necessary. As a result, better follow-up can improve treatment adherence and continuity of care.

3. For Families:

Family involvement should be encouraged whenever possible because strong family support can help patients accept their diagnosis and continue treatment. When patients feel understood and supported at home, they are more likely to overcome fear and stigma. Therefore, family participation plays an important role in successful HIV care.

4. For Communities:

Community education and HIV awareness programs should be strengthened to reduce stigma and correct wrong beliefs about HIV and ART. Many patients refuse treatment because of fear of discrimination and misunderstanding about the disease. By increasing public awareness and acceptance, communities can create a safer and more supportive environment for people living with HIV.

5. For Healthcare Institutions:

Healthcare institutions should provide emotional and professional support for nurses handling HIV cases, especially those dealing with treatment refusal and emotionally difficult situations. Since nurses also experience stress and emotional burden, support systems such as training programs and mental health services are necessary. This can improve both nurse well-being and the quality of patient care.

6. For Future Researchers:

Future researchers should include the perspectives of people living with HIV who refuse ART, as well as other healthcare professionals such as doctors, counselors, and case managers, to provide a more comprehensive understanding of treatment refusal from different viewpoints. They may also include participants from other provinces or HIV treatment hubs and explore interventions that improve patient readiness, reduce stigma, and strengthen ART adherence. These studies can contribute to the development of more effective strategies for improving HIV care and patient outcomes.

7. Implications to Nursing Practice:

The findings of this study highlight that nursing practice in HIV care should focus more on patient-centered care, effective communication, and emotional support. Nurses play a key role in helping patients move toward treatment readiness by providing continuous counseling, education, and compassionate care. In addition, nurses should strengthen their ability to handle stigma-related concerns and ethical challenges while respecting patient autonomy. Therefore, integrating empathy, patience, and strong communication skills in nursing practice can improve patient trust, encourage ART acceptance, and enhance overall quality of HIV care.

Compliance with Ethical Standards

The researchers ensured that the study was conducted in accordance with established ethical principles and research standards. Informed consent was obtained from all participants before their involvement in the study. They were properly informed of the study's purpose, procedures, and potential risks, and were assured that their participation was entirely voluntary. Participants were also given the freedom to refuse to answer any question or withdraw from the study at any time without experiencing any negative consequences. Throughout the research process, the anonymity of the participants was maintained by excluding identifying information from the presentation and discussion of the findings. The researchers also complied with the Data Privacy Act of 2012 (Republic Act No. 10173) by ensuring that all collected information was handled confidentially, securely stored, and accessed only by authorized members of the research team for academic and research purposes.

Furthermore, the researchers prioritized the participants' well-being by maintaining a respectful, supportive, and nonjudgmental environment during the interviews. Appropriate measures were taken to minimize possible discomfort, and participants were allowed to skip questions or discontinue their participation whenever they wished. The researchers declare that no conflict of interest existed in the conduct of this study and that personal interests or relationships did not influence the selection of participants, data collection, analysis, or interpretation of the findings. Plagiarism was strictly avoided by properly acknowledging and citing all sources used in the research.

Objectivity and fairness were maintained throughout the analysis and interpretation of the participants' responses to minimize personal bias and ensure that the findings accurately represented their experiences. The results of the study were used purely for academic and research purposes and were not intended for any commercial or personal gain.

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