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Stigma and Discrimination in HIV Care: A pilot study in a public hospital

Azliha Minai Rejab[1], Azlini Chik[1*], Jheffany Yazid[2], Sulistyo Andarmoyo[3]

**Corresponding Author*

[1] Faculty of Social Sciences and Applied Sciences, Universiti Sultan Zainal Abidin, Kuala Nerus, Terengganu, Malaysia.
[2] ILKKM Kubang Kerian (Nursing), Ministry of Health, Kota Bahru, Kelantan, Malaysia
[3] Falkulti Kesihatan, Universitas Muhammadiyah Ponorogo, Jawa Timur, Indonesia

cumie.geeha@gmail.com, azlinichik@unisza.edu.my, jheffany1988@gmail.com, sulistyoandarmoyo@gmail.com
Tel: +60122256314

Abstract
People living with HIV (PLHIV) in Malaysia face stigma and discrimination both in healthcare and the community, often fueled by negative media portrayals. This qualitative pilot study explored the experiences of five PLHIV receiving treatment in a public hospital. Findings revealed supportive healthcare interactions but also challenges, including access to HAART and discriminatory practices. Social support from family, NGOs, and healthcare providers was crucial in maintaining resilience and motivation. The study highlights the urgent need for stigma-reduction interventions, positive media portrayals, and strengthened support systems to improve PLHIV's quality of life.

Keywords: Stigma; Discrimination; PLHIV; Social Support

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1.0 Introduction

Human Immunodeficiency Virus (HIV) remains a critical global public health concern, with approximately 39 million people living with HIV (PLHIV) worldwide in 2022 (UNAIDS, 2023). Despite major advances in antiretroviral therapy (ART) that have significantly improved survival rates and reduced disease progression, PLHIV continue to face numerous challenges beyond clinical treatment. Among these challenges, stigma and discrimination remain persistent barriers that affect treatment adherence, psychological well-being, and overall quality of life. Globally, multiple studies have shown that negative societal perceptions towards HIV contribute to reduced healthcare engagement and increased psychosocial burden among affected individuals.

In Malaysia, HIV continues to pose a serious health issue, with 63,158 individuals actively receiving ART in 2022 (Ministry of Health Malaysia, 2023). While significant efforts have been made to improve early detection and treatment, societal and healthcare-related stigma remains prevalent. National data indicate that approximately 78.7% of Malaysians still hold discriminatory attitudes towards PLHIV (Jusoh et al., 2020). These attitudes manifest both within the community and in healthcare settings, where patients have reported experiencing prejudice, labeling, and reduced quality of care. Although previous studies have explored general perceptions of HIV-related stigma, limited evidence exists on how these experiences affect PLHIV's treatment engagement, emotional resilience, and access to social support systems in Malaysian healthcare contexts.

Given these gaps, this study was conducted to explore the lived experiences of stigma and discrimination among PLHIV receiving treatment in a public hospital and to examine the role of social support systems, including family, healthcare professionals, and non-

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governmental organizations, in helping patients cope with stigma and improve treatment adherence. Understanding these experiences is crucial for identifying psychosocial challenges, improving patient-centered care, and informing the development of targeted interventions to reduce stigma and enhance the quality of life of PLHIV in Malaysia.

2.0 Literature Review

HIV-related stigma is a multidimensional phenomenon that encompasses societal rejection, discrimination within healthcare settings, and internalized self-stigma among people living with HIV (PLHIV) (Hedge et al., 2021; Turi et al., 2021). Previous studies have highlighted that stigma occurring in healthcare environments can be particularly damaging, as it directly influences patients' willingness to access services and adhere to antiretroviral therapy (ART) (Earnshaw et al., 2023). For instance, practices such as labeling patient beds with red marks or separating PLHIV into different spaces during clinical care have been reported to reinforce social marginalization and generate distrust towards healthcare providers. Such discriminatory experiences reduce patients' confidence in the healthcare system and negatively affect their overall engagement with treatment and psychosocial well-being.

Community-level stigma is further amplified by negative media portrayals, including sensationalist news and harmful social media commentary, which have been shown to diminish PLHIV's self-confidence and exacerbate feelings of shame (Mendonca et al., 2023; Obeagu et al., 2024). In Malaysia, studies indicate that up to 48.6% of PLHIV report experiencing perceived stigma, while more than 40% describe having inadequate access to social support systems (Turi et al., 2021). These findings highlight that HIV-related stigma is not only rooted in the healthcare environment but also perpetuated within broader social structures. Media-driven narratives and community-level prejudice often shape individuals' perceptions of PLHIV, contributing to further social exclusion and compounding the psychosocial burden faced by affected individuals.

Social support has consistently been identified as a critical protective factor in mitigating the negative effects of stigma and improving the quality of life (QoL) among PLHIV. Support from family, peers, and non-governmental organizations (NGOs) provides emotional stability, enhances coping mechanisms, and encourages treatment adherence (Armoon et al., 2022). However, despite the demonstrated benefits of psychosocial support, many PLHIV remain hesitant to seek help due to fears of confidentiality breaches and the risk of further discrimination (Chong et al., 2021). This reluctance suggests that structural barriers and deeply rooted perceptions continue to limit access to effective support systems, even when they are available.

3.0 Materials and Methods

3.1 Study Design

This study employed a qualitative approach using a pilot study design. The purpose of using a pilot study was to explore the experiences of people living with HIV (PLHIV) in relation to stigma, discrimination, and social support while receiving treatment at a public hospital. The pilot study design was selected because it allows researchers to identify potential challenges, refine research tools, and test the methodological feasibility before conducting a full-scale study.

3.2 Study Setting

The study was conducted at a public hospital that provides comprehensive HIV treatment services and serves as a major referral center for HIV patients. This hospital was strategically chosen as the setting because it offers access to a diverse population of PLHIV who are actively receiving care and management for their condition.

3.3 Population and Sampling

The study population consisted of PLHIV who were undergoing treatment at the selected public hospital during the study period. A total of five participants were recruited for this pilot study, which was considered an adequate sample size for an initial qualitative exploration where the goal is to obtain rich, descriptive, and detailed data rather than statistical generalization. Purposive sampling was applied to ensure that all participants met specific inclusion criteria relevant to the study's objectives. The inclusion criteria required that participants be PLHIV currently receiving treatment at the hospital, aged between 18 and 65 years, able to communicate in either Malay or English, capable of providing written informed consent, and willing to participate in in-depth interviews which were audio-recorded.

3.4 Study Instrument

Data were collected using a semi-structured interview questionnaire developed in Malay, which was designed based on an extensive literature review and thematic guidelines relevant to HIV care, stigma, discrimination, and social support. The questionnaire was structured to allow participants the flexibility to elaborate on their experiences while ensuring coverage of key areas. The interview guide was organized into three main sections. The first section focused on collecting demographic information, including age, gender, ethnicity, educational background, and occupation. The second section explored participants' experiences with stigma and discrimination in HIV care, including the types of stigmas encountered, the effects of stigma on treatment adherence, and the factors contributing to

stigmatizing behaviors. This semi-structured design ensured consistency across interviews while enabling flexibility to probe deeper when needed.

3.5 Validation of Study Instrument

The interview questionnaire underwent a rigorous validation process to ensure its content accuracy, clarity, and relevance to the study objectives. It was reviewed by a panel of four experts comprising two medical specialists in infectious disease control and two senior lecturers specializing in public health and qualitative research. The medical specialists evaluated the instrument's content validity to ensure that the questions addressed key aspects of HIV care, stigma, and discrimination. At the same time, the academic experts assessed the methodological rigor, thematic structure, and suitability for qualitative exploration.

3.6 Data Collection Methods

Data collection was conducted through face-to-face, semi-structured interviews with the participants at a private and secure location within the hospital to ensure comfort, privacy, and confidentiality. Prior to each interview, participants were briefed about the study objectives, procedures, and ethical considerations, after which written informed consent was obtained. Each interview lasted between 30 to 60 minutes and was audio-recorded with participants' permission to ensure accurate transcription. During the interviews, researchers encouraged open and honest sharing by creating a supportive environment and actively listening to participants' narratives. Field notes were also taken to capture non-verbal cues and contextual observations that complemented the audio-recorded data. Upon completion of the interviews, all data were stored securely in password-protected digital folders accessible only to the principal investigator to maintain confidentiality and data integrity.

3.7 Data Analysis

Data were analyzed using thematic analysis supported by the Atlas.TI software to systematically organize and interpret the qualitative findings. The analysis began with the verbatim transcription of interview recordings to ensure the accuracy of participants' responses. Transcripts were then read repeatedly to allow for familiarization with the data, after which initial codes were assigned to relevant segments of the text. These codes were grouped into broader themes and subthemes that reflected patterns in the participants' experiences. The interpretation stage involved relating the identified themes to the study's objectives and situating them within the context of HIV care and stigma. To ensure the credibility and trustworthiness of the findings, two independent reviewers cross-checked the coding framework and thematic structure, with discrepancies resolved through discussion and consensus.

3.8 Ethical Considerations

Ethical approval for this study was obtained from the National Medical Research Register (NMRR), reference number RSCH ID-23-03386-BJZ, and from the Medical Research and Ethics Committee (MREC), reference number NMRR ID-23-02426-POK (IIR). All participants were informed about the purpose of the study, its procedures, and their rights prior to participation, and written informed consent was obtained from each respondent. To maintain confidentiality, participants' identities were anonymized, and audio recordings and transcripts were securely stored in password-protected digital folders accessible only to the principal investigator. In accordance with ethical guidelines, all collected data will be permanently deleted upon completion of the study to ensure the protection of participants' privacy.

4.0 Results

4.1 Socio-demographic Characteristics

As presented in Table 1, the socio-demographic characteristics of the participants demonstrated a relatively homogeneous profile in terms of gender and ethnicity. The demographic profile highlights that while the participants were similar in gender and ethnicity, their educational, occupational, and treatment-related backgrounds contributed to unique experiences that influenced their perceptions of stigma, discrimination, and social support.

Table 1. Socio-demographic of participants (n=5)

Gender	Ethnicity	Education	Occupation	Duration of HIV
Male	Malay	Degree	Self-employed	10 years
Male	Malay	Secondary School	Self-employed	6 years
Male	Malay	Diploma/ skills certificate	Unemployed/ Retired	23 years
Male	Malay	Degree	Private sector	1 year
Male	Malay	Diploma	Private sector	2 years

Remarks: All participants are male and of Malay ethnicity.

4.2 Themes, Subthemes, and Participant Quotations

The thematic analysis revealed four overarching themes that captured participants lived experiences: (i) experiences of HIV treatment, (ii) stigma and discrimination in care, (iii) the impact of media on self-confidence, and (iv) the role of social support systems. Each theme comprises several subthemes that provide deeper insights into how participants perceived, interpreted, and coped with their situations.

These findings address the study's objectives by exploring the complex interplay between social stigma, healthcare-related discrimination, and the role of support systems in shaping treatment experiences.

Table 2. Theme, subthemes, and quotations from participants (n=5)

Theme	Subtheme	Description	Quotation
Experience of HIV Treatment	Positive Experiences in HIV Care	Healthcare staff showing empathy and providing moral support.	"The staff were handsome and never showed stigma, always offering encouragement." (R1)
	Negative Experiences in HIV Care	Lack of access to medication (e.g., HAART) and discrimination by healthcare staff.	"Problems began when advised to take HAART." (R3)
Stigma and Discrimination in Care	Discrimination in Healthcare Facilities	Presence of labels or special marks on HIV patients' beds and prejudiced attitudes.	"There was a red star marking placed at the head of the bed, and it was large." (R3)
	Social Stigma from the Community	Negative comments on social media and societal perceptions of HIV patients.	"Reading netizens' comments affects our self-confidence." (R1)
	Self-Stigma	Feelings of inferiority due to societal views impact motivation to seek treatment.	"Fear-inducing media coverage causes internal stigma and reduces motivation." (R3)
Impact of Media on Self-Confidence	Impact of social media on Stigma	Harmful exposure through social media comments.	"Recently, there has been a lot of media exposure about HIV, and when reading netizens' comments, it affects our self-confidence." (R1)
	Fear-Inducing Health Campaigns	Health awareness campaigns that induce fear and low self-esteem.	"Health awareness advertisements in the media, such as on television and billboards, are frightening." (R3)
Social Support System	Support from Family and Friends	The role of family in boosting the confidence of HIV patients.	"My family greatly supports me morally and emotionally." (R4)
	Support from Non-Governmental Organizations (NGOs)	NGOs like PT Foundation play a crucial role in providing moral and material support.	"PT Foundation helps in terms of emotions and providing information about treatment." (R5)
	Support from Healthcare Professionals	The role of doctors and nurses in motivating HIV patients to continue treatment.	"Doctors and nurses are very caring and help in providing moral and mental support." (R2)

5.0 Discussion

5.1 Experiences of HIV Treatment

The findings indicate that the experiences of HIV treatment among participants are dualistic, encompassing both positive and negative aspects. Positive experiences primarily involve the supportive and empathetic attitudes of healthcare staff, which play a crucial role in maintaining patients' motivation to continue treatment. One participant expressed his satisfaction by stating, " The staff were handsome and never showed stigma, always offering encouragement" (R1). This statement highlights that when healthcare providers exhibit non-judgmental and caring attitudes, it significantly enhances the well-being of PLHIV. This finding is consistent with previous studies indicating that positive interactions with healthcare providers improve treatment adherence and overall health outcomes (Armoon et al., 2022).

However, there were also negative experiences reported, particularly related to accessing HAART and encountering discriminatory practices within healthcare facilities. One participant described the difficulty in obtaining HAART, where uncertainties regarding supply and the need to purchase medication independently caused emotional stress. Additionally, the use of special marks on patients' beds, such as a red star symbol, was perceived as a form of discrimination, negatively impacting patients' mental health. This practice not only perpetuates stigma but also erodes patients' trust in healthcare services (Hedge et al., 2021).

This finding aligns with previous research conducted in Iran, which identified barriers in healthcare services for HIV patients, including fear of facing healthcare providers and inappropriate behavior from healthcare staff (Earnshaw et al., 2023). Similarly, a study in the United States involving 76 women living with HIV reported that participants described fears and experiences of stigma in healthcare settings, including privacy violations, disrespect for patient autonomy, and reproductive coercion. These negative experiences significantly influenced their adherence to HIV treatment recommendations.

5.2 Stigma and Discrimination in Healthcare

Stigma within healthcare settings remains a major challenge for PLHIV. Discriminatory practices, such as labeling patients' beds and displaying prejudiced attitudes, contribute to feelings of isolation and anxiety among patients. Previous studies have also reported that such discriminatory practices not only reduce the quality of care but also increase psychological distress among HIV patients.

A study by Matoy et al. (2024) revealed that healthcare workers (HCWs) often fear being overwhelmed by listening to women's traumatic experiences, or worry about causing problems within the patients' families, leading to biased attitudes. This highlights the gap in training and awareness among healthcare workers regarding HIV-sensitive care. Furthermore, Chong et al. (2021) found that PLHIV reported a lack of confidentiality and perceived discriminatory behavior at public health facilities, which served as a significant barrier to testing and treatment adherence (Mendonca et al., 2023).

Social stigma from the community, often shaped by media portrayals, also contributes to internalized stigma among PLHIV. One participant reflected, " Reading netizens' comments affects our self-confidence" (R1). This indicates that negative social narratives can shape self-perception and influence health-seeking behavior. Internalized stigma is particularly detrimental as it reduces patients' motivation to continue treatment, thereby negatively affecting their well-being (Fauk, Hawke, et al., 2021).

Moreover, Mendonca et al. (2023) reported that social connectedness significantly improves the quality of life (QoL) among PLHIV. The study found that stronger social connections help mitigate the effects of HIV-related stigma, although mental health symptomatology did not significantly moderate this relationship. These findings underscore the importance of addressing both healthcare-based stigma and societal stigma to foster better psychosocial outcomes for PLHIV.

5.3 Impact of Media on Self-Confidence

Media plays a crucial role in shaping public perceptions of HIV. The findings indicate that social media often becomes a source of stigma, especially through negative comments. One participant stated, "Lately banyak juga media expose pasal HIV dan bila baca komen netizen it affects our self-confidence" (R1). Such negative portrayals not only increase stigma within the community but also lead to internalized stigma among PLHIV, reducing their self-confidence and motivation to continue treatment.

This finding is consistent with Obeagu et al. (2024), who reported that stigma on social media negatively impacts the mental health of PLHIV, causing feelings of shame and social isolation. Similarly, Rich et al. (2022) noted that negative comments on social media amplify societal stigma and directly affect the psychological well-being of patients, leading to reduced engagement with healthcare services.

Additionally, fear-based health awareness campaigns also negatively affect self-confidence. One participant shared, "Fear-inducing media coverage causes internal stigma and reduces motivation" (R3). Aghaei et al. (2023) supported this by stating that fear-driven messages can deter patients from seeking treatment and increase internalized stigma.

In contrast, campaigns that focus on normalizing HIV and creating supportive environments are more effective in reducing stigma (Aghaei et al., 2023). For example, the HealthMindr app has been shown to improve HIV testing and PrEP uptake through a supportive and non-judgmental approach (Rosen et al., 2022). Moreover, Shaari and AlghmAdi, (2024) highlighted that peer support and positive discussions significantly enhance the well-being of PLHIV. Therefore, it is crucial to adopt media strategies that promote inclusivity and support, rather than fear, to enhance the self-confidence of PLHIV and encourage consistent healthcare engagement.

5.4 Social Support System

Social support is found to play a crucial role in helping PLHIV cope with stigma. Participants reported that support from family, healthcare professionals, and NGOs was essential in maintaining their motivation to continue treatment. One participant stated, " My family greatly supports me morally and emotionally" (R4). Such support enhances patient resilience and helps them confront social stigma, aligning with previous studies that emphasize the role of social support in strengthening treatment motivation (Fauk, Hawke, et al., 2021; Shaari and Alghmadi, 2024).

These findings are consistent with research by Reddy and Berry, (2022), which highlighted that participants expressed a desire for community support groups, education, and increased use of interpreters to address social barriers that hinder full adherence to HIV medication. This indicates that community-based support systems are crucial for addressing the psychosocial challenges faced by PLHIV.

Furthermore, NGOs such as PT Foundation play a vital role in providing both moral and material support to PLHIV. One participant noted, " PT Foundation helps in terms of emotions and providing information about treatment " (R5). These organizations act as crucial intermediaries, connecting patients with more inclusive healthcare services and offering ongoing psychosocial support. However, a study by Turi et al. (2021) found that more than two-fifths of PLHIV reported having inadequate social support, highlighting the ongoing need for strengthened community networks. Similarly, Chong et al. (2021) reported that while PLHIV were generally satisfied with their HIV treatment, they seldom sought psychosocial support to protect their privacy. This finding underscores that despite recognizing the benefits of social support, PLHIV may still avoid seeking help due to concerns about confidentiality.

These findings have broader implications that extend beyond the immediate study context. Improving HIV care requires a multi-level approach that integrates patient-centered practices, stigma-reduction strategies, and stronger community engagement. Healthcare institutions should enhance anti-stigma training among healthcare providers to ensure respectful, confidential, and non-discriminatory care for PLHIV. In addition, policymakers and NGOs can work collaboratively to expand access to psychosocial support services and public education programs that address misconceptions about HIV. Reframing health communication strategies is also critical; shifting from fear-based campaigns towards empowering, inclusive messaging can improve treatment adherence and reduce self-stigma.

6.0 Conclusion and Recommendation

This pilot study confirms that stigma and discrimination remain substantial challenges in the delivery of HIV care within public healthcare settings. These barriers continue to erode the confidence and healthcare-seeking behavior of individuals living with HIV. Although several participants described positive interactions with compassionate healthcare providers, many also recounted experiences of prejudice and exclusion that negatively affected their engagement with treatment. Social support, especially from family members, healthcare professionals, and non-governmental organizations, was identified as a protective factor in coping with the psychological burden of stigma. While these findings provide important insights, they should be interpreted within the context of a pilot study. The small sample size and single-site focus limit the generalizability of the results; however, the rich, qualitative narratives highlight critical themes that warrant further exploration. Future research should expand on these insights by exploring context-specific strategies to reduce discrimination, improve patient-provider relationships, and promote a healthcare environment grounded in empathy, inclusivity, and respect. Strengthening community awareness and reforming media portrayals of HIV are also essential steps towards ensuring the dignity and well-being of people living with HIV.

Conflict of Interest
The authors declare that there are no conflicts of interest.

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Paper Contribution to the Related Field of Study
This paper contributes to the understanding of stigma, discrimination, and social support among PLHIV in Malaysia, providing valuable insights for healthcare policy, stigma-reduction interventions, and the improvement of patient-centered HIV care.

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