

Stigma and Discrimination in HIV Care: A Pilot Study in a Public Hospital

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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 pressing global public health concern, with approximately 39 million people living with HIV (PLHIV) worldwide in 2022 (UNAIDS, 2023). Despite advances in antiretroviral therapy (ART), stigma and discrimination persist, affecting treatment adherence, mental health, and the overall quality of life (QoL) of PLHIV.

In Malaysia, the prevalence of HIV has shown a steady increase, with 63,158 people actively receiving ART in 2022 (Ministry of Health Malaysia, 2023). However, national surveys reveal that 78.7% of Malaysians hold discriminatory attitudes towards PLHIV (Jusoh et al., 2020). These attitudes manifest not only in the community but also within healthcare settings, where patients frequently encounter prejudicial treatment and reduced quality of care (Elamin et al., 2019; Fauk, Ward, et al., 2021).

This study aims to explore the lived experiences of stigma, discrimination, and social support among PLHIV receiving treatment in Malaysian public hospitals, with the goal of informing targeted interventions to improve healthcare outcomes and psychosocial well-being.

2.0 Literature Review:

HIV-related stigma is a multidimensional issue encompassing societal rejection, healthcare discrimination, and internalized self-stigma (Hedge et al., 2021; Turi et al., 2021). Research has shown that stigma in healthcare is particularly damaging, as it directly influences patients' willingness to access services and adhere to treatment (Earnshaw et al., 2023). For example, labeling patient beds with red marks or using segregated spaces in clinics reinforces social marginalization and fosters distrust.

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Community stigma is further amplified by negative media portrayals, including sensationalist news and harmful social media comments, which diminish the self-confidence of PLHIV and exacerbate feelings of shame (Mendonca et al., 2023; Obeagu et al., 2024). Studies in Malaysia reveal that up to 48.6% of PLHIV experience perceived stigma, while more than 40% report inadequate social support (Turi et al., 2021).

Social support, particularly from family, peers, and non-governmental organizations (NGOs), has been consistently identified as a protective factor that mitigates the effects of stigma and enhances QoL (Armoon et al., 2022). Yet, many PLHIV remain hesitant to seek psychosocial help due to fears of confidentiality breaches and further discrimination (Chong et al., 2021). Addressing stigma requires not only healthcare reforms but also media strategies and community education efforts that promote inclusivity and empathy (Aghaei et al., 2023).

3.0 Materials and Methods

3.1 Study Design

This study employs a qualitative approach using a pilot study design. The purpose of this pilot study is to explore the experiences of people living with HIV (PLHIV) in the context of stigma, discrimination, and social support while receiving treatment at a public hospital. The pilot study design was chosen because it allows for the identification of key issues and the testing of methodological suitability before conducting a full-scale study. The qualitative approach was selected as it provides an in-depth understanding of the experiences and perspectives of PLHIV within healthcare settings. This method also enables researchers to examine psychosocial issues that may not be captured through quantitative research.

3.2 Study Setting

This study was conducted at a public hospital that provides HIV treatment services. The hospital was chosen because it serves as a major referral center for HIV patients and offers access to the relevant study population. This strategic location allows the researcher to gather data from participants with direct experience in receiving HIV care.

3.3 Population and Sampling

The study population consists of PLHIV currently receiving treatment at the selected public hospital. The pilot study involved a sample size of five participants. This sample size is deemed sufficient for initial exploration in a qualitative study, where the focus is on obtaining rich and detailed data. The study uses purposive sampling to ensure that the participants meet the inclusion criteria. The inclusion criteria are as follows:

- PLHIV currently undergoing treatment at the public hospital.
- Aged between 18 and 65 years.
- Able to provide written consent to participate in the study.
- Capable of communicating in Malay or English.
- Willing to be interviewed and audio-recorded.

3.4 Study Instrument

The instrument used in this study is a semi-structured interview questionnaire in Malay. The questionnaire was developed based on a literature review and thematic guidelines related to HIV care, stigma, discrimination, and social support.

The interview questions are divided into three main sections:

- Demographic Information: Age, gender, ethnicity, educational level, and occupation.
- Experiences of Stigma and Discrimination in HIV Care: Experiences of receiving treatment, types of stigmas or discrimination encountered, the impact of stigma on treatment, and factors contributing to stigma.
- Strategies to Reduce Stigma and Discrimination: Perspectives on support from healthcare staff, suggestions for improving services, and participants' hopes for future HIV care.

3.5 Validation of Study Instrument

The interview questionnaire was reviewed and validated by four experts, comprising two medical specialists in infectious disease control and two senior lecturers specializing in public health and qualitative research. The medical specialists ensured content validity related to HIV care aspects, while the academic experts reinforced the methodological rigor and thematic relevance.

The validation process involved evaluating the structure of the questionnaire, the appropriateness of questions, and language clarity to ensure that the instrument could generate valid and reliable data. Feedback from the experts was incorporated to refine the instrument to suit the pilot study context.

3.6 Data Collection Methods

Data collection was carried out using face-to-face semi-structured interviews. These sessions were conducted in private and comfortable environments to uphold participants' confidentiality and ensure their ease throughout the process. Each interview lasted approximately 30 to 60 minutes and was audio-recorded with the informed consent of the participants. The entire data collection process was

systematically guided by ethical considerations and aimed to facilitate open, honest sharing of experiences relevant to the study objectives:

- Providing detailed information about the study's objectives and obtaining written consent from participants.
- Conducting in-depth face-to-face interviews in a comfortable setting.
- Recording interviews with participants' permission.
- Storing data securely and maintaining participant confidentiality.
- Taking field notes to capture non-verbal observations during the interviews.

3.7 Data Analysis

Data were analyzed using thematic analysis with the assistance of the Atlas.ti software. The analysis process involved several stages:

- Transcription: Interview recordings were transcribed verbatim.
- Initial Coding: Categorizing data into relevant codes.
- Theme Development: Grouping codes into main themes and subthemes.
- Interpretation: Relating themes to participants' experiences and the context of HIV care.
- Validation: Conducting cross-checking with two independent reviewers to ensure accuracy and validity of the themes.

3.8 Ethical Considerations

This study obtained ethical clearance from the National Medical Research Register (NMRR), reference number RSCH ID-23-03386-BJZ, and approval from the Medical Research and Ethics Committee (MREC), reference number NMRR ID-23-02426-POK (IIR). Prior to participation, all respondents were provided with detailed information regarding the study's objectives, procedures, and their rights. Informed written consent was obtained from each participant. All data were securely stored in password-protected digital folders accessible only to the principal investigator. To uphold confidentiality, the collected data will be permanently deleted following the completion of the study.

4.0 Results

4.1 Socio-demographic Characteristics

As shown in Table 1, the socio-demographic characteristics of participants indicate a homogeneous profile. The study involved five male participants, all of whom were of Malay ethnicity, reflecting a homogeneous profile in terms of gender and ethnicity. In terms of educational background, two participants hold Degree qualifications, one completed secondary school, and two possess a diploma or skills certificate. Regarding occupation, two participants are self-employed, two work in the private sector, and one is unemployed/retired. The duration of living with HIV among participants varied, with one having lived with HIV for 10 years, one for 6 years, one for 1 year, one for 2 years, and one for 23 years.

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

Table 2 presents key themes and subthemes from participants' experiences, focusing on HIV treatment, stigma, media impact, and social support. Participants described both positive care experiences and challenges such as HAART access and discriminatory practices. Social media and health campaigns affected self-confidence, while family, NGOs, and healthcare professionals provided crucial moral and informational support.

Table 2. Theme, subthemes and quotation 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, impacting 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	Negative 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)	The role of NGOs like PT Foundation 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

This study aimed to explore the perceptions of stigma, discrimination, and social support among people living with HIV (PLHIV) who receive treatment in a public hospital. The findings revealed both positive and negative experiences in HIV care, highlighting the complexity of stigma and its impact on patients' lives. Four main themes emerged from the thematic analysis: experiences of HIV treatment, stigma and discrimination in healthcare, the impact of media on self-confidence, and the role of social support systems.

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.

Additionally, previous studies support the notion that discrimination within healthcare settings hinders patients from seeking continuous care. For instance, Hedge et al. (2021) and Elamin et al. (2019) highlighted that discriminatory attitudes from healthcare providers significantly reduce patients' motivation to pursue treatment. This suggests that challenges in HIV care extend beyond treatment availability, emphasizing the need for supportive and non-stigmatizing healthcare environments.

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 collectively highlight that while social support significantly enhances treatment adherence and emotional well-being, challenges such as social stigma and privacy concerns continue to hinder optimal engagement with support systems. Therefore, fostering environments where PLHIV feel safe to seek support without fear of exposure is essential. Increasing awareness among healthcare providers regarding the importance of maintaining confidentiality and offering non-judgmental care is critical for improving the quality of life for PLHIV.

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. The limited sample size and single-site focus of the study restrict the extent to which findings may be generalized to broader populations. 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 in the conduct and reporting of this research.

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Paper Contribution to 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. The findings inform future research and practice in public health, social work, and healthcare management.

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