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Posted Date: 24 April 2025

doi: 10.20944/preprints202504.2040.v1

Keywords: stigma; discrimination; HIV; AIDS; Indonesia



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Review

# Manifestation and Marking of HIV Stigma in Indonesia: A Scoping Review

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**Abstract:** A comprehensive understanding of HIV stigma is crucial for designing effective stigma interventions. This scoping review offers an overview of the manifestations and markings of HIV stigma in Indonesia. Articles published in PubMed, Scopus, Google Scholar, and other sources were searched. Studies selected were published between 2019 and 2023, written in English, and focused on the manifestations or markings of HIV stigma in Indonesia. A thematic approach was applied to analyse the findings. From an initial pool of 4,776 articles, 745 advanced to the title and abstract screening process, with 40 ultimately included in the review. The findings indicate HIV related stigma toward People Living with HIV (PLHIV) in Indonesia can manifest in various forms, including avoidance of contact with PLHIV, differential treatment of PLHIV, negative reactions toward PLHIV, and self-stigma. These stigmatizing behaviors were observed across various societal levels, including family members, the general public, colleagues in the workplaces, healthcare providers, and even PLHIV themselves. The findings further revealed the dual burden of stigma experienced by vulnerable populations such as children, adolescents, pregnant women, and key populations. Additionally, this review noted the presence of stigma marking directed at PLHIV, portraying them as dangerous, unclean, immoral, bad and irresponsible, and even sinners. In conclusion, In Indonesia, HIV stigma may take many different forms and occurs in many different society levels. This underscores the need for comprehensive, collective action, and cross-sectoral interventions to effectively address these issues.

**Keywords:** stigma; discrimination; HIV; AIDS; Indonesia

## 1. Introduction

HIV continues to represent a substantial public health challenge in Indonesia, with a cumulative total of 377,650 cases were reported as of March 2023. Based on the type of population, 27.7% of new HIV cases identified in the country between January and March 2023 were among men who have sex with men (MSM), 3.3% were sex workers, 1.1% were transgender individuals, 0.5% were people who inject drugs (PWID), and the remainder were distributed across other populations such as pregnant women, individuals with high-risk partners, and others [1].

Indonesia has implemented various strategies to address the HIV epidemic in the country, including expanding the coverage of self-HIV screening, virtual interventions to reach key populations, access to Pre-Exposure Prophylaxis (PrEP) services, differentiated care services, "test and treat" strategies, and mentoring programs for healthcare professionals at health facilities [2]. Despite these efforts, the outcomes of these programs appear to fall short of the expected targets. As of March 2023, only 85% of people living with HIV (PLHIV) were aware of their status, 42% received antiretroviral therapy, and just 27% had achieved viral load suppression, indicating significant gaps

in program effectiveness [1]. Evidence suggests that stigma and discrimination faced by PLHIV may have contributed to these challenges [3–7].

Stigma, as defined by Goffman, is a deeply discrediting attribute that alters an individual's social identity, transforming them from being perceived as whole to being viewed as flawed and marginalized [8]. In the context of HIV, stigma involves negative attitudes and beliefs towards PLHIV [9]. UNAIDS broadens the definition of HIV-related stigma to encompass all forms of stigma and discrimination that affects the response to HIV, including factors such as gender identity, sexual orientation, drug use, sex work, and HIV status [10]. The HIV-related stigma poses significant barriers to the success of HIV prevention and control efforts. It has a profoundly negative impact on PLHIV, contributing to increased HIV prevalence [11], challenges in treatment adherence [12], decisions around HIV testing [13], and difficulties in disclosing HIV status [14]. At least two studies in Indonesia further confirmed this effect. A study in Papua showed that PLHIV who experienced stigma were less likely to adhere to their treatment (OR = 0.53; 95% CI = 0.32-0.89) [15]. Beyond its direct effect on HIV prevention programs, a study in Malang also found that PLHIV who reported lower levels of HIV-related stigma tended to have a better quality of life [16]. This indicates the needs to prioritize the development of interventions to address HIV-related stigma in Indonesia to support the country's achieving its targets in HIV mitigation programs.

The Health Stigma and Discrimination Framework, emphasizes the importance of thoroughly understanding the manifestations and markings of HIV stigma to develop more specific and effective interventions [17]. However, a comprehensive review exploring the variations in HIV stigma manifestations and markings in Indonesia remains lacking. To address this gap, this scoping review was conducted to systematically map and analyze these variations, providing a clearer understanding of how HIV stigma is expressed in Indonesia.

## 2. Materials and Methods

This research is part of a broader review aimed at exploring HIV stigma in Indonesia, with the goal of providing a comprehensive overview of the manifestations and markings of HIV stigma in the country. This study adhered to the PRISMA for Scoping Reviews (PRISMA-ScR) guidelines [18] and was guided by the scoping review framework developed by Arksey and O'Malley [19]. The PRISMA-ScR checklist is available in supplementary material. While a review protocol was developed, it was not registered.

### 2.1. Literature Search

To identify relevant documents, a literature search was conducted from January to March 2024 using electronic databases covering studies from 2019 to 2023, along with other sources. The search strategy is presented in the following section.

#### 2.1.1. Electronic Databases

The search was conducted in PubMed, Scopus, and Google Scholar using combinations of various keywords synthesized from previous similar studies [11,20–22]. The list of keywords used can be found in supplementary materials. In addition to using keywords, the literature search applied a publication date filter (2019-2023). To download the combined results of the literature search from Google Scholar and Scopus in CSV format, the researchers used assistance of the Publish or Perish application [23]. The results of the literature from the search at PubMed were downloaded directly from the PubMed website.

#### 2.1.3. Reference List Searches

The reference lists of studies selected and passed the full article screening stage were also examined to identify additional literature.

## 2.2. Inclusion Criteria

Studies were included if they were:

1. Published or conducted between January 1, 2019, and December 31, 2023: This criterion was applied to ensure that the data was relevant to the current situation of HIV stigma.
2. Written in English: This was done to enhance the accessibility of the literature for global academic analysis.
3. Conducted in Indonesia: This criterion was used to obtain data specific to the context of HIV stigma in Indonesia.
4. Contained findings related to the manifestations or markings of HIV stigma in Indonesia: This was done to ensure that the literature directly addressed the objectives of the review.
5. Not review research: Primary research studies were prioritized to provide original data and insights, rather than relying on secondary analyses.

## 2.4. Literature Selection

### 2.4.1. Abstract and Title Screening

All articles were imported into Microsoft Excel for processing. During the title and abstract screening stage, NKS identified the presence of the keyword's "stigma" and "HIV" within the titles and abstracts. This identification was facilitated using the "Search" function in Microsoft Excel. The keywords "stigma" and "HIV" were pre-determined based on a synthesis of keywords and terms commonly used in global studies on HIV stigma. Duplicate entries were identified at this stage through the "Conditional Formatting" feature in Microsoft Excel, which highlighted duplication based on similarities in titles and authors. The list of keywords used in the abstract and title screening can be found in the supplementary material.

### 2.4.1. Full Article Screening

During the full-article screening stage, NKS conducted a review of all the literature that passed the title and abstract screening. NKS assessed the alignment of literature with the predetermined inclusion criteria. In addition, a manual duplication screening was performed, during which NKS examined similarities in titles, authors, and the overall content. The entire screening process was carried out using Microsoft Excel, which included an inclusion criteria checklist. Articles that met all the inclusion criteria at this stage were deemed eligible for inclusion in the review. The entire screening file was shared via OneDrive with all team members for review.

## 2.5. Data Charting

Data charting was performed using standardized forms approved by all research team members. The team members determined that the information charted was essential and contributed to the overall research findings. The charting process was conducted using Microsoft Excel, which was shared via OneDrive, allowing all team members to review the charting process performed by each member.

## 2.6. Data Items

In this review, the information sought was categorized into three themes: manifestations, marking, and levels of HIV stigma. The manifestation of HIV stigma is the embodiment of HIV stigma marking, which can include experiences of stigma and discrimination, internalized stigma, perceived stigma, anticipated stigma, secondary stigma, stereotypes, negative prejudice, stigmatizing attitudes, and discriminatory behaviors. Conversely, marking refers to the labelling of an individual due to certain health conditions or other perceived differences such as race, class, gender, sexual orientation, or occupation [17]. The manifestation of HIV stigma in this review was defined as any form of negative reactions or actions related to HIV exhibited by an individual or group towards PLHIV and

populations associated with PLHIV. On the other hand, marking was defined as any form of negative labelling or judgment related to HIV directed by an individual or group towards PLHIV and populations associated with PLHIV. Finally, the level of stigma was defined as the results of a quantitative study that indicates the prevalence of HIV-related stigma or discrimination in a particular region or population.

2.7. Synthesis Result Method

In synthesizing the results, we used a thematic analysis approach [24], where identified findings were grouped into relevant themes and then elaborated into a cohesive narrative. The process of forming group themes began with coding the review findings, categorizing the coding results and sub-themes, and establishing the main themes based on the identified categories and sub-themes. In grouping the themes, we followed The Health Stigma and Discrimination Framework to categorize findings into relevant themes or subthemes.

3. Results

A total of 4,776 articles were identified. Out of these, 745 passed the title and abstract screening stage, while 40 advanced to full-text article screening stage, resulting in 40 articles included in this review. Figure 1: PRISMA Flow Diagram of Literature Selection provided more detailed information about the literature selection process.

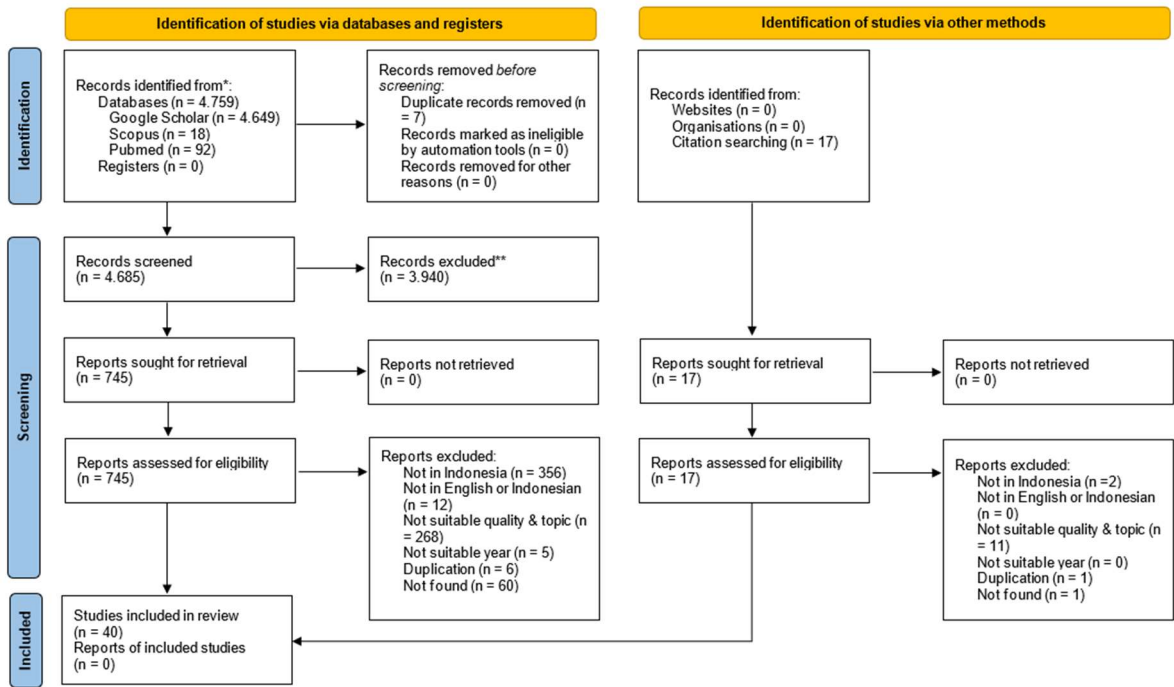


Figure 1. PRISMA Flow Diagram of Literature Selection.

Of the 40 studies included, almost a third (32%) were published in 2022. The majority of studies employed qualitative methods (63%), with data sources predominantly consisting of primary data (85%). Geographically, almost half of the research was conducted within the top 10 provinces with the highest number of PLHIV receiving antiretroviral (ARV) in 2021 (40%). Specifically, among these 10 provinces, a significant number of studies were conducted in West Java (12%) and Jakarta (12%). Despite a significant number of PLHIV living in other provinces such as Riau and Central Java, no studies were found in these two settings, highlighting the uneven geographical distribution of studies. More detail information can be found in Table 1: Literature Characteristics. All literature included in the review can be found in supplementary materials.

**Table 1.** Literature Characteristics.

Category	Sub-category	Number (%)
Publication Year	2019	4 (10%)
	2020	7 (18%)
	2021	11 (28%)
	2022	13 (32%)
	2023	5 (12%)
Research Method	Qualitative	25 (63%)
	Quantitative	15 (37%)
Data Source Type	Primary	34 (85%)
	Secondary	6 (15%)
Research Locations <sup>1</sup>	Ten provinces with the most PLHIV on ARV	16 (40%)
	Other provinces	15 (38%)
	General Indonesia	9 (23%)
Detail 10 provinces with the most PLHIV on ARV <sup>1</sup>	DKI Jakarta	5 (12%)
	East Java	2 (5%)
	West Java	5 (12%)
	Central Java	0 (0%)
	Bali	3 (7%)
	Papua	3 (7%)
	North Sumatera	1 (2%)
	South Sumatera	2 (5%)
	Banten	1 (2%)
	Riau Island	0 (0%)
Findings <sup>2</sup>	Manifestation	30 (75%)
	Marking	11 (27%)
N= 40		

<sup>1</sup>There were studies conducted in more than one location. <sup>2</sup>There were studies that contained more than one category of findings.

The results were then divided into three main themes, including: the situation of HIV-related stigma in Indonesia, the manifestations of HIV-related stigma in Indonesia, and the markings of HIV-related stigma in Indonesia.

3.1. *The Situation of HIV-Related Stigma in Indonesia*

Studies indicated that HIV stigma was prevalent among healthcare providers, the wider community, as well as among younger groups such as students and adolescents. The measurement of HIV-related stigma across various groups has been conducted by numerous studies employing diverse HIV stigma indicators. For instance, a study in Gunung Kidul focused on healthcare workers in community health centers and a hospital, assessed HIV stigma through four key indicators: expressing fear of contracting HIV from PLHIV, holding negative perceptions toward PLHIV, refusing to provide healthcare services to PLHIV, and engaging in discriminatory practices by taking excessive precautionary measures when treating PLHIV. This study found that more than 50% of healthcare workers in both community health centers and hospitals expressed fear of contracting HIV

from PLHIV, held negative perceptions toward PLHIV, refused to provide healthcare services to them, or engaged in discriminatory practices by taking excessive precautions while treating PLHIV [25].

The measurement of HIV-related stigma has also been conducted at the family level. One study assessed the extent of HIV stigma within families by analyzing respondents' answers to questions regarding their willingness to hide a family member's HIV status and feelings of shame associated with having a family member living with HIV. These responses were then defined as discriminatory behaviors related to HIV within the family. The study's findings revealed a high prevalence of discriminatory behaviors related to HIV within families. Specifically, more than 70% of respondents from the general population exhibited such discriminatory behaviors [26].

Furthermore, the measurement of HIV-related stigma at the general population level was identified in four studies. All four studies utilized secondary data from the 2017 Indonesia Demographic and Health Survey (IDHS). Despite relying on the same data source, these studies employed different perspectives, focused on varying sociodemographic characteristics and used distinct HIV stigma indicators. Nevertheless, the findings across all four studies were consistent, revealing that more than 50% of study subjects exhibited discriminatory behaviors related to HIV. More specifically, over 60% of the total respondents demonstrated such behavior [27,28], with more than 50% of both male [29] and female [29,30] respondents engaged in discriminatory actions when analyzed by gender.

In addition to assessing the overall extent of HIV-related stigma in the general population, several studies have focused specifically on measuring HIV stigma by young people. One study found that HIV-related stigma behaviors were also present among young individuals. Using the same data previously mentioned, the study revealed that 13.6% of women exhibiting discriminatory attitudes toward HIV were aged 15-19 years old [29]. Additionally, another study with the same data source found that 85.9% of respondents aged 15-22 demonstrated stigmatizing attitudes [31].

In addition to measuring the percentage of respondents using HIV stigma indicators, several studies assessed the extent of HIV-related stigma through scoring systems. One commonly employed scoring method is The AIDS-Related Stigma Scale [32]. This instrument consists of 12 self-reported questions designed to evaluate public perceptions of HIV-related stigma toward individuals living with HIV. Responses were recorded using a 4-point Likert scale, ranging from "strongly disagree" to "strongly agree." The total score ranges from 12 to 48, with higher scores indicating higher levels of stigma. Utilizing this method, one study reported that the average HIV stigma score among pharmacy staff in several provinces in Indonesia and pharmaceutical students from Java was  $21.02 \pm 4.65$  and  $20.66 \pm 4.41$ , respectively [33]. This indicated that the stigma scores of both respondent groups did not exceed half of the maximum HIV stigma score, suggesting that the HIV stigma levels in these groups were relatively low.

Another scoring method used to measure the extent of HIV-related stigma was through a questionnaire developed by researchers based on prior preliminary studies. Using this method, one study developed a questionnaire consisting of 16 items, evaluated using a Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). The maximum total score that could be achieved was 80. The cutoff value to identify supportive attitudes was set at a score of 20, where higher scores indicate less supportive or more stigmatizing attitudes. This study found that 99.6% of dietetic students from three universities on Java Island reported high stigma scores, with a mean score of  $42.7 \pm 0.27$  [34].

Scoring methods were also employed to measure the extent of HIV-related stigma among nursing, midwifery, and medical students in Jakarta, Surabaya, and Jayapura. In this study, HIV stigma was assessed using the Nurses' Attitudes AIDS Scale (NAAS). The HIV stigma score was obtained by averaging the responses of the participants across 41 questionnaire items. This study found that nursing, midwifery, and medical students had an average stigma score of 3.15, with 5 being the maximum possible score [35]. This indicated that the level of HIV stigma found across all student groups falls within the moderate to high category.

The measurement of HIV-related stigma found in the studies not only examined the perspective of those who perpetuated the stigma but also considered the extent of stigma reported or experienced by those who received it. The studies involved a diverse range of respondent groups, including Men who have Sex with Men (MSM), women living with HIV, and PLHIV in general. Two studies found a relatively high percentage of MSM experiencing HIV stigma. Specifically, 50% of MSM in two healthcare facilities located in Jakarta reported high levels of HIV-related stigma [36]. Another study in Bukittinggi City found that 82% of MSM reported experiencing HIV-related stigma and discrimination [37]. Stigma was not only prevalent among MSM, but studies also found that HIV-related stigma was notably high among women living with HIV. Approximately 50.8% of women with HIV at Dr. H. Abdul Moeloek General Hospital reported high levels of HIV-related stigma [3]. However, although three studies found relatively high levels of HIV stigma in certain groups across various locations, the extent of HIV stigma among PLHIV in general was found to be low in a study conducted in Bali, with a mean score of 42.88 (SD  $\pm$  17.59), while the maximum possible mean score was 100 [38].

### 3.2. *The Manifestations of HIV-Related Stigma in Indonesia*

A range of variations in the manifestations of HIV-related stigma was noted in some studies. The elaboration of findings on this theme will be divided into six sub-themes, as follows.

#### 3.2.1. Avoiding Contact with PLHIV as a Common Manifestation of HIV-Related Stigma

Although the manifestations of HIV stigma vary depending on the location, avoiding contact with PLHIV might be the most common form of HIV stigma. Seven studies found that the act of avoiding interaction with PLHIV occurred at the family level. The fear of contracting HIV often leads members to physically distanced themselves from PLHIV [39–41]. Family members had also explicitly prohibited PLHIV from approaching or making contact with their children [41,42], or have even refused to visit PLHIV [43]. In addition to the avoidance of direct physical contact with PLHIV, another form of avoidance found within families was the reluctance to handle items associated with PLHIV. Some family members refused to touch the clothing of PLHIV due to the mistaken belief that HIV can be spread this way [44]. Spouses of PLHIV have also shared instances where family members moved out of their nearby homes fearing that HIV could be transmitted through shared water sources [43].

Beyond the family setting, nine studies found that the avoidance of physical contact with PLHIV was also practiced by the community members surrounding PLHIV. PLHIV reported instances of physical avoidance, particularly by neighbors, who refrained from shaking hands or sitting in the same chair [6,39,44–46], touching their hands, eating together [6], or even communicating with them [47]. There were PLHIV shared their experience of attending a public place of worship, where no one was willing to shake hands with them, despite handshaking being common among others [45]. Furthermore, society often viewed PLHIV as violators of social norms, to the point that people avoided even walking past their homes [46]. Furthermore, regarding the avoidance of contact in the community, two studies reported that communities also refused to consume food touched by PLHIV [42,45]. This avoidance behavior extended even after PLHIV's death. This was expressed by healthcare workers in a qualitative study, stating that when a PLHIV passed away, the entire community refused to consume food and drink served, avoided approaching the body, and wore masks out of fear of transmissions [39]. This widespread avoidance has led many PLHIV to hesitate in disclosing their HIV-positive status, fearing social ostracization [40]. Along with misconceptions about how HIV is transmitted, a study also highlighted a community's limited understanding of ARV treatment. PLHIV reported that despite adhering to ARV treatment, community members continued to avoid contact with them out of fear of HIV transmission [5].

Regrettably, two studies found that some instances of contact avoidance escalated to the outright expulsion of PLHIV. PLHIV shared that disclosing their HIV status to the family provoked anger

within the family, leading to near expulsion [45]. Not only by family members, PLHIV were expelled from their villages by the community once their HIV status became known [4].

Avoidance of contact by healthcare workers was also reported, as admitted by the healthcare workers, peer support groups, and PLHIV themselves. For instance, three studies noted that healthcare workers acknowledged that many of their colleagues in healthcare facilities hesitated and refused to serve PLHIV [48], often citing reasons such as lack of knowledge and fear of contracting HIV, leading them to avoid physical examinations [39,49]. In another study, peers supporters also reported instances where some healthcare workers refused to administer treatments involving the genital areas of PLHIV, such as inserting medication [50]. PLHIV further recalled situations where healthcare workers denied services upon discovering their HIV status [51].

Beyond direct refusals, PLHIV often faced indefinite delays in receiving non-HIV-related healthcare services once their HIV status became known [45]. Another study in Papua found that healthcare workers' refusals to provide care provoked anger among PLHIV, who demanded their right to access services, leading to a doctor's eventual intervention [7].

The avoidance of PLHIV in healthcare settings was found not only to be experienced by patients but also by PLHIV working in healthcare services. A study noted that PLHIV's wife recounted how her husband was shunned by his colleagues despite working at a primary healthcare facility, demonstrating how HIV stigma can also affect PLHIV in the workplace [43].

### 3.2.2. Different Treatment by Those Willing to Interact with PLHIV

Studies indicated that not all individuals who stigmatized PLHIV completely avoided contact with them. However, those who did maintain contact often subjected PLHIV to different, and at times discriminatory, treatment. This behavior was observed both in family and healthcare providers. In two studies, PLHIV reported that even while living with their families, they experienced differential treatment from other family members. This included the separation of personal items, such as dining utensils, which were specially marked for them [39,45]. The practice extended to food and water designated for PLHIV, a study stated that with some family members requiring PLHIV to wash their dishes and clean the toilet after use [45]. There were even instances where food was delivered to PLHIV through a gap under the door, as though feeding a confined pet [39,45]. Some families even boiled PLHIV's clothes before washing them to prevent transmission to other family members [45]. PLHIV expressed that this separation of personal items makes them feel isolated and abandoned by their families [39]. Ironically, this separation of personal items occurred even in families that otherwise supported the PLHIV's treatment [7]. To overcome stigma, PLHIV often chose to isolate themselves, driven by the harsh treatment they faced from their families after disclosing their HIV status [52].

In healthcare settings, PLHIV often experienced differential treatments, particularly through excessive self-protection measures taken by healthcare workers. For example, some healthcare workers were reported to wear double gloves and repeatedly washed their hands after providing care, making PLHIV felt stigmatized and dehumanized [44]. Furthermore, PLHIV reported being placed on beds at the end of the room, separated from other patients. Some also recounted being rushed to complete their treatment even when their condition was not stable, leading to their re-admission to the hospital due to deteriorating health. In certain cases, these individuals were then placed in isolation rooms under the justification of having a dangerous HIV-related disease [51]. The same was found in another study, with PLHIV only being allowed hospitalization if they agreed to be placed in a private room [48].

In addition to direct discrimination from individuals within the home setting and healthcare facilities, one study found that PLHIV also experienced differential treatment in the workplace. This included being dismissed or rejected from employment at certain institutions due to HIV status, leading PLHIV to prefer working in NGOs related to their health condition or starting their own business to avoid HIV-related stigma in traditional work environments [48].

### 3.2.3. Negative Social Reactions to PLHIV

Another form of HIV stigma manifestation identified in the study was negative social reactions. Negative social reactions to PLHIV were sometimes manifested through unsympathetic comments from community members, often their closest friends. These individuals, aware of PLHIV's past risky behaviors, remarked that the HIV status of both the PLHIV and their daughter was a punishment for their past actions, specifically having multiple sexual partners before marriage. These comments left the PLHIV feeling shocked and depressed, as they had not expected such negative views from those closest to them [53]. Additionally, gossip about PLHIV's status was also prevalent within the community. PLHIV shared that issue for years, where their HIV status had been the subject of gossip [45,46]. This gossip was not confined to individuals without a healthcare background but was also spread by healthcare professionals, who disclosed the PLHIV's HIV status to the community, contributing to the spread of information within the community [4,39,45].

In addition to gossiping, three studies observed another adverse social reaction in healthcare settings. Healthcare workers often expressed anger towards PLHIV while providing care. Some healthcare workers reported feeling particularly frustrated towards PLHIV, who contracted HIV through risky sexual behaviors, such as engaging with commercial sex workers, despite having a legitimate partner. This anger was driven by sympathy for the PLHIV's partners, who had to endure the consequences of their spouse's infidelity, and the associated emotional pain [39]. Furthermore, in one study, PLHIV recounted instances where healthcare workers displayed anger and physical violence upon learning of their HIV status after receiving healthcare services. In that study, a PLHIV noted that a healthcare worker expressed a preference for treating COVID-19 patients over HIV patients, even during the COVID-19 pandemic [54]. Additionally, some PLHIV reported being reprimanded by a midwife during their pregnancy, who asserted that PLHIV should not be pregnant, leading to emotional distress for the PLHIV involved [43].

Healthcare workers in healthcare settings also often make unsympathetic comments towards PLHIV and key populations. These callous comments included questions or statements that offended PLHIV. For instance, two studies found that some healthcare workers admitted that their colleagues intentionally asked probing questions related to the risky behaviors that led to the PLHIV contracting HIV, such as "Why are you gay?" [45] or accusing the PLHIV's husband of having had sex with a sex worker [43].

### 3.2.4. Self-Stigma

The review findings revealed that experiences of stigma encountered by PLHIV evoked significant fear and anxiety. This condition drove them to avoid locations perceived as potential sources of stigma, including healthcare facilities, which in turn might have hindered their access to essential care and treatment. Healthcare providers reported that one of the reasons for PLHIV's non-compliance with ARVs is their fear of the challenges they may face when accessing services [5]. PLHIV also expressed concerns about being ostracized upon disclosing their condition, including the possibility of healthcare providers refusing to offer care [5,54].

Not limited to healthcare services, the review findings also indicated that PLHIV often experienced significant fear and anxiety when disclosing their HIV status to family members. PLHIV feared the reaction of their family members upon learning their HIV-positive status, as well as the potential for discrimination similar to that faced by other PLHIV, such as rejection by family and community to perform burial rituals for them [44]. This rejection not only led to avoidance of interactions, but also created reluctance among PLHIV to disclose their status due to fear of being subjected to various forms of bullying from their friends [55].

In addition to fear and anxiety, studies also identified self-stigma in the form of a loss of self-confidence. One study highlighted that PLHIV reported losing pride in themselves and feeling low self-worth [47]. PLHIV expressed this loss of pride due to the loss of opportunities to achieve their aspirations because of their HIV-positive status, which ultimately also brought sadness and trauma.

Some PLHIV also disclosed that HIV caused so much suffering that they even considered ending their lives to escape it [56].

In addition to the feelings mentioned above, studies revealed that many PLHIV experienced feelings of guilt and sinfulness, especially those who engaged in risky sexual behavior. These feelings were intensified by societal stigma and discrimination, particularly in a culture where PLHIV were perceived as unclean, and associated with other stigmatized communities, such as MSM, transgender, sex workers. As a result, PLHIV felt that they were being judged as part of these communities, regardless of their identity [44]. One study noted various ranges of emotions upon learning their HIV status. Some PLHIV could accept their diagnosis due to the acknowledgment of their past behaviours. Nevertheless, they remained concerned about the potential impact on their spouse and children, who may also be infected [57].

### 3.2.5. HIV Stigma Among Children, Adolescents, Pregnant Women, and Key Populations.

HIV stigma can significantly harm children, adolescents, pregnant women, and key populations. These groups were specifically highlighted because they had already been categorized as vulnerable populations even before being affected by HIV, which further heightened their susceptibility to stigma and its negative impacts.

Among Children Living with HIV (CLHIV), stigma hindered their access to healthcare services. There were five studies that show how stigma related HIV might impede CLHIV in several ways. One study found that healthcare providers refused to offer services to CLHIV; demanding someone with HIV-negative status to accompany the child for ARV services [42]. Additionally, another study noted that healthcare providers were reported to have used double gloves when providing services to children because their parents were PLHIV [45]. In another instance, PLHIV recounted their experience of their child, also living with HIV, being denied access to the hospital restroom during a healthcare visit [45,53]. Similarly, one study noted an occurrence where children of PLHIV were placed in isolation, such as being assigned to the end bed in wards reserved for B20 patients, with healthcare providers responsible for changing bed linens donning full personal protective equipment including gowns, masks, and double gloves [51]. These examples highlight the significant challenges faced by children of PLHIV in accessing healthcare services due to their or their parents' HIV status.

Not only did they face barriers due to HIV related stigma from healthcare workers, CLHIV who became aware of their HIV status often experienced feelings of disappointment, shock, and sadness. Some families, in an attempt to shield their children from stigma, even restricted them from forming friendships to prevent their HIV status from being disclosed. Another effort made by families to conceal their child's HIV status included avoiding access to government-provided services, such as formula milk assistance, health insurance, and peer-support groups, further isolating the children from potential sources of support [58].

HIV-related stigma not only affected PLHIV but also significantly impacted key populations, creating profound barriers to accessing healthcare services and support. A quantitative study revealed that almost half (11 out of 29) of MSM (men who have sex with men) experienced rejection from family members, adding to the challenges they faced in seeking support [59]. Within healthcare settings, stigma was equally pervasive. In Gunung Kidul, 64% of community health center staff admitted to refusing services to key populations whenever possible [25]. Additionally, 9 out of 209 MSM reported being rejected outright by healthcare providers, many of whom expressed discomfort or disgust during their first interactions with MSM patients [49]. Verbal stigma and moral judgments further exacerbated the issue. Three studies found that individuals who disclosed their sexual orientation to aid in diagnosis were often met with lengthy religious lectures, with their orientation described as sinful [5,39,60].

Although study on HIV stigma among adolescents were limited, one study found that 11 out of 29 young people living with HIV experienced aversion or rejection from their family or friends [59]. This suggested that adolescents within key populations or those living with HIV may face similarly severe impacts from HIV stigma.

HIV-related stigma also affected pregnant women. While it wasn't commonly found among studies included in this review, one study reported that a pregnant woman, although HIV-negative herself, was denied healthcare services during her pregnancy check-ups, due to her husband's HIV-positive status [43]. This showed how a partner's HIV status could affect a pregnant woman's access to healthcare service. Additionally, pregnant women also faced significant human rights violations. One study recounted the experience of a 22-year-old woman living with HIV who was coerced into signing a sterilization consent form before delivering her child, with the threat that surgery would not proceed unless she complied [48]. This example illustrated how HIV can intersect with human rights.

### 3.2.6. Gradual Changes in HIV-Related Stigma Within Communities

Studies also revealed positive outcomes, indicating a change in how HIV stigma was perceived within society. Although not frequently reported in the literature, fortunately improvement in the situations has been seen, with one study observing that while people were once completely unwilling to interact with them, they had been at least willing to engage in conversation with them, albeit from a certain distance [43]. Similarly, a study found that some community members claimed they would behave kindly towards PLHIV but still kept their distance [47].

### 3.3. *The Markings of HIV-Related Stigma in Indonesia*

Several HIV stigma markings were identified as causes of the stigma experienced PLHIV. Studies indicated that PLHIV were not only marked as individuals with HIV but were also associated with negative characteristics related to the perceived modes of HIV transmission according to societal beliefs. Healthcare providers conveyed that families and communities perceived PLHIV as dangerous individuals, largely due to the perception of HIV as a severe disease [39,41,46,47]. Some families also believed that an individual's HIV status was a form of divine curse for what they perceived as "dirty" behavior, including drug use, sex work, and other actions deemed sinful [45,58]. Additionally, PLHIV expressed that society's understanding of HIV transmission was limited, associating it primarily with unprotected sex or sex work. Hence, PLHIV were often marked as immoral individuals, reinforcing the stigma tied to promiscuous behavior [45].

One study reported the occurrence where PLHIV reported being labelled as "bad mothers" [4]. This misconception stemmed from the belief in society that "good" mothers cannot contract HIV, with HIV viewed as a "dirty" disease transmitted through promiscuous behavior. One of the studies included in the review also highlighted the experiences PLHIV during childbirth, where upon disclosing their HIV status to healthcare providers, it led to immediate moral judgment from the healthcare providers. These women were further perceived as irresponsible mothers, primarily due to assumptions about their engagement in promiscuous behaviour. However, PLHIV expressed that by disclosing their status, they aim to protect their children from HIV infection [54]. Similarly, three studies stated female PLHIV often being stigmatized as "hina" or morally degraded women [43,46,54]. On the other hand, a study found that the community viewed being HIV positive as caused by risky sexual behaviour and as punishment from God [58].

## 4. Discussion

This study aims to explore the manifestations and markings of HIV-related stigma experienced by PLHIV in Indonesia. The review revealed that, while numerous studies on HIV stigma have been conducted in Indonesia, their geographic distribution remained uneven. For instance, although the Riau Islands and Central Java provinces rank among the top ten provinces with the highest numbers of PLHIV on ARV in 2021, no studies on HIV stigma that met this review's inclusion criteria were identified from these two provinces. The number of PLHIV on ARV in a region may reflect both significant healthcare access among PLHIV and, indirectly, a substantial population of PLHIV. Consequently, conducting research on HIV stigma in these areas is essential to elucidate stigma-

related challenges faced by a large population of PLHIV. While it is important to acknowledge that the inclusion criteria employed in this review may limit the range of literature included, the uneven geographical distribution of studies might indicate that future research on HIV stigma should encompass underrepresented regions to facilitate a more comprehensive understanding of the complexities of HIV stigma across Indonesia.

This review indicates that HIV-related stigma continues to be a significant issue across various sectors of Indonesian society. The manifestations of HIV-related stigma have been identified across various groups, including families, communities, students, adolescents, colleagues in workplaces, healthcare workers, and even PLHIV themselves. Interestingly, most of the causes of this stigma stem from a lack of knowledge or misunderstandings regarding HIV transmission [5,39,42,43,49]. Therefore, educational efforts might be the critical strategy in addressing HIV-related stigma across various groups. Additionally, psychological support from healthcare services or HIV-related communities might be essential for PLHIV to mitigate self-stigma.

The lack of understanding regarding HIV also leads to various negative labels being assigned to PLHIV, often based on misconceptions about HIV transmission [4,43,45,46,54,58]. HIV can be contracted through routes that should not be deemed immoral acts. For example, a child may acquire HIV from their parents, a wife from her spouse, or a healthcare worker who is accidentally infected through a needle-stick injury. This aspect should be emphasized in the educational content provided to the general public. In addition to understanding HIV transmission, it is equally important for the public to recognize the positive impact of ARV therapy for PLHIV. ARV therapy as prescribed can suppress HIV viral load in PLHIV, not only benefiting their health but also reducing the risk of transmission to others [61]. This knowledge is essential for the general public to foster increased support for the treatment and well-being of PLHIV.

In addition to reflecting inadequate dissemination of information related to HIV, the manifestations and markings of HIV stigma identified in this review indicate that PLHIV frequently faced restrictions on their fundamental rights. For instance, within healthcare services, PLHIV encountered refusal or delays in receiving care, as well as the use of derogatory language in response to their HIV status. Such behavior highlights violations of patients' rights to equitable and inclusive healthcare [62]. Moreover, this behavior of HIV-related stigma extended beyond adult PLHIV to other vulnerable groups such as CLHIV, ALHIV, pregnant women with HIV, and other key populations. Therefore, providing educational training on HIV stigma alone is insufficient. Training should also include guidelines on communication, interaction, and care provision for PLHIV and vulnerable populations, to ensure more inclusive services and better protection of patient rights. In addition, the presence of strong regulations to protect the human rights of PLHIV may also be necessary to ensure equality of rights for PLHIV in healthcare settings, society, and the workplace.

Studies indicated that PLHIV perceived certain healthcare procedures as conveying a sense of stigma towards them, such as placement in isolation rooms or separate areas, as well as the use of B20 labeling [51]. Therefore, a comprehensive review of healthcare procedures should be considered. The procedures implemented should avoid including unnecessary measures that could potentially offend PLHIV. Furthermore, effective communication with patients can serve as a solution to address these issues.

This review indicated that the knowledge and perceptions of those who perpetrate stigma might be the key factors in why individuals engaged in stigmatizing actions or held stigmatizing attitudes. However, various other studies have identified additional factors contributing to the formation of HIV stigma, such as residential location [27,30,44] and workplace setting [25,63]. Given this, the intervention approaches developed should not solely focus on increasing knowledge and changing perceptions through one-time educational efforts. A more comprehensive approach, such as collective action approach involving the participation of multiple sectors to achieve shared goals could be an effective strategy to address HIV stigma in Indonesia. Collective action allows individuals or groups affected by HIV to collaborate in overcoming the social, cultural, and systemic barriers that hinder access to healthcare services. Similar to the study conducted in Thailand, the

potential of collective action was demonstrated through efforts by the MSM community and male-to-female transgender individuals living with HIV. In this study, the community worked together to learn from each other and teach strategies for combating stigma, including stigma originating from social environments, families, and healthcare providers [64].

Although studies included in this review indicate that the percentage of HIV stigma remains high, it is important to note that most studies used data collected before 2019. Improvements in the situation might have occurred, particularly considering more recent public health interventions and awareness campaigns aimed at addressing stigma. Future studies would benefit from exploring whether these interventions have led to a significant reduction in HIV-related stigma in more recent years. In addition, this review adopted a scoping review design to gain a preliminary understanding of the current issues surrounding HIV-related stigma in Indonesia. For a more in-depth exploration, future research could employ a systematic review approach to complement these findings, providing a more comprehensive and detailed picture of the extent and nature of HIV stigma in the country. This would offer stronger evidence to inform interventions and policy recommendations aimed at addressing these critical issues.

## 5. Conclusions

HIV stigma continues to persist in Indonesia, manifesting in various forms. It occurs across multiple layers and sectors, including families, communities, students, adolescents, workplaces, healthcare workers, and even PLHIV themselves. These actions of stigma have significant consequences for affected groups, such as adult PLHIV, CLHIV, ALHIV, pregnant women, and key populations, leading to reduced access to healthcare services and adverse psychological effects, among other negative outcomes. The persistence of stigma is fueled by negative labelling and exaggerated fears among those perpetuating it. Therefore, efforts to intervene, including improving understanding of HIV among PLHIV, their families, communities, workplaces, healthcare providers, might be crucial. Comprehensive interventions such as collective action might be essential for eradicating HIV stigma in Indonesia. In addition, the establishment of a strong regulatory framework might be critical to ensure equal opportunities and fair treatment for PLHIV, particularly in securing access to healthcare, social participation, and employment.

**Supplementary Materials:** The following supporting information can be downloaded at: [https://drive.google.com/drive/folders/1ie\\_xYSrcTxG7fr-fPObbQSxjOH8bvJD0?usp=drive\\_link](https://drive.google.com/drive/folders/1ie_xYSrcTxG7fr-fPObbQSxjOH8bvJD0?usp=drive_link)

**Author Contributions:** Conceptualization, P.P.J. and N.K.S.; methodology, N.K.S.; software, N.K.S. and L.P.L.W.; validation, N.K.S., P.P.J. and L.P.L.W.; formal analysis, N.K.S.; investigation, N.K.S.; writing—original draft preparation, N.K.S.; writing—review and editing, N.K.S., P.P.J. and L.P.L.W.; visualization, N.K.S.; supervision, P.P.J.; project administration, N.K.S. All authors have read and agreed to the published version of the manuscript.”

**Funding:** This research received no external funding.

**Institutional Review Board Statement:** The study was approved by the Ethics Committee of Faculty of Medicine Udayana University (0337/UN14.2.2.VII.14/LT/2024 and January 24, 2024)

**Data Availability Statement:** There is no data supporting the reported results in this study that has been uploaded to Google Drive.

**Acknowledgments:** We would like to extend our sincere gratitude to Dr. Anak Agung Sagung Sawitri, MPH, Dinar Saurmauli Lubis, S.KM., M.P.H., PhD, and Dr. Ni Putu Widarini, S.KM., M.PH, esteemed lecturers at Udayana University, for their invaluable guidance and insightful feedback throughout the course of this research. Furthermore, we express our deep appreciation to all the authors of the studies included in this review. Their contributions of materials and sources of information have significantly enriched our work and provided a solid foundation for this review.

**Conflicts of Interest:** The author is affiliated with a research institution actively engaged in HIV prevention studies. Additionally, personal and professional interests may influence the interpretation and reporting of findings. This affiliation and personal interests have been disclosed and considered in the review process to ensure transparency and objectivity.

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