

## Stigma and Quality of Life Among Pre-elderly with HIV in Jakarta, Indonesia

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### Abstract

**Background:** The quality of life (QoL) of people living with HIV (PLWHIV) is affected by physical, psychological, social, and spiritual aspects. During the pre-elderly period (ages 45–59 years), these aspects become major challenges. Stigma is one of the social aspects that may be related to QoL among PLWHIV. This study aimed to examine the correlation between stigma and QoL among pre-elderly with HIV.

**Methods:** This was an analytical observational study with a cross-sectional design, conducted from July 2022 to August 2023 in health services and online-based HIV communities in Jakarta, Indonesia. Sampling was performed using convenience sampling, including 120 pre-elderly living with HIV. Data were collected online using Google Forms. Stigma was assessed using the Berger HIV Stigma Scale, while QoL was measured using the WHOQOL-HIV BREF questionnaire. Data were analyzed using Spearman's rank correlation test in SPSS.

**Results:** Most participants were male (62.5%). The highest median scores in stigma domains were public attitudes (41) and personalized stigma (36). For QoL, the highest median scores were in the physical and spiritual domains (both 15). Personalized stigma and disclosure concerns were negatively correlated with the physical, psychological, independence, and spiritual QoL domains ( $p<0.05$ ). Negative self-image demonstrated negative correlations with all QoL domains ( $p<0.05$ ).

**Conclusions:** Stigma is negatively correlated with the quality of life among pre-elderly with HIV in Jakarta. The greater the stigma experienced, the lower their quality of life. Further research using qualitative methods such as in-depth interviews, is recommended to explore the correlation of each stigma domain with the quality of life.

**Keywords:** HIV, pre-elderly, quality of life, stigma

Althea Medical Journal.

2025;12(2):85-94

Received: May 16, 2024

Accepted: October 22, 2024

Published: June 30, 2025

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## Introduction

Human immunodeficiency virus (HIV) is a virus that attacks the immune system. Without comprehensive intervention, HIV can progress to a more severe condition known as acquired immunodeficiency syndrome (AIDS).<sup>1</sup> In 2022, Indonesia reported 338,760 cases of HIV, with the majority occurring among individuals aged 25–49 years (68.1%). In contrast, those aged over 50 years accounted for the smallest proportion (9%).<sup>2</sup> As a progressive disease, HIV impacts many domains of well-being, including physical, psychological, social, and

spiritual aspects. One of the most significant social factors affecting people living with HIV (PLWHIV) is stigma, which has a profound negative impact on their quality of life (QoL). HIV-related stigma refers to negative perceptions, attitudes, and discriminatory behaviors directed toward individuals living with HIV. Globally, around 34% of PLWHIV experience severe stigma, and 66% report moderate stigma. This phenomenon also affects pre-elderly individuals (45–59 years) living with HIV, who face heightened challenges due to aging including a higher risk of comorbidities, neurocognitive dysfunction,

increased feelings of loneliness, declining health status, and persistent HIV/AIDS-related stigma.<sup>3</sup> However, data regarding HIV-related stigma specifically within the pre-elderly population remain limited.

Several factors contribute to the perpetuation of HIV-related stigma, including inadequate public knowledge about the disease, misconceptions regarding its modes of transmission, and the social narrative surrounding HIV/AIDS.<sup>4</sup> Moreover, the widespread assumptions that individuals over 50 are less likely to engage in high-risk sexual behavior or contract sexually transmitted infections, reinforce age-related stigma.<sup>5</sup> The impact of stigma extends beyond social exclusion, contributing to poor psychological well-being, increased anxiety, depression, and diminished mental health.<sup>6</sup> Stigmatization also leads to reduced social support and barriers to accessing healthcare service, negatively affecting treatment adherence and outcomes.<sup>7</sup> Furthermore, fear of disclosing one's HIV status due to stigma often results in delayed treatment initiation, further compromising the quality of life.<sup>8</sup>

Despite the significant influence of stigma, research examining its relationship with the quality of life among pre-elderly PLWHIV remains limited. Therefore, this study aimed to investigate the correlation between various dimensions of stigma and the quality of life among pre-elderly individuals living with HIV in Jakarta, Indonesia. The findings are expected to enhance understanding of how stigma affects this population and to inform strategies that promote better psychosocial well-being and quality of life for pre-elderly PLWHIV.

## Methods

This analytical observational with a cross-sectional design was conducted from July 2022 to August 2023 in both healthcare facilities and online-based HIV communities in Jakarta, Indonesia. Participants were selected through convenience sampling and included pre-elderly individuals aged 45–59 years living with HIV. The study was approved by the Ethics Committee of Atma Jaya Catholic University of Indonesia with the approval number 12/03/KEP-FKIKUAJ/2023.

After providing written informed consent, participants completed a demographic questionnaire that collected data on age, gender, education level, marital status, monthly income, employment status, and domicile. The monthly income classification was based

on the Jakarta Provincial Minimum Wage for 2023, which was Rp4,901,798.<sup>9</sup>

HIV-related stigma was measured using the Indonesian version of the Berger HIV Stigma Scale, and quality of life was assessed using the World Health Organization Quality of Life HIV Bref (WHOQOL-HIV BREF) questionnaire.

The Berger HIV Stigma Scale had previously been tested for validity and reliability, resulting in a Cronbach's alpha of 0.94. This scale consisted of 40 items divided into 4 domains: personalized stigma, disclosure concern, public attitudes, and negative self-image. Each item was rated on a 4-point Likert scale (1=strongly disagree, 2=disagree, 3=agree, and 4=strongly agree). Items 8 and 21 were negative statements and therefore reverse-scored. The total possible score for the Berger HIV Stigma Scale ranged from 40 to 160, with domain-specific as follows: personalized stigma (18–72), disclosure concerns (10–40), negative self-image (13–52) and public attitudes (20–80). There was no cutoff point in stigma assessment, thus, the assessment was evaluated based on the obtained scores. The higher the score, the more severe the stigma experienced.<sup>10,11</sup>

The WHOQOL-HIV BREF questionnaire had been tested for validity and reliability with a Cronbach's Alpha of 0.66. This questionnaire consisted of 31 items with 6 domains: physical health, psychological well-being, independence level, social relationship, environment, and spirituality. Each item was rated on a 5-point Likert scale. Negative items (items 3, 4, 5, 8, 9, 10, and 31) were reverse-scored. There was no cutoff point to determine quality of life whether it was good or bad. The higher the score obtained, the higher the quality of life experienced.<sup>12</sup>

For categorical variables, data were presented as frequencies and percentages. Numerical data (age) were tested using the Kolmogorov-Smirnov test and reported as median and interquartile range (IQR). Correlations between the stigma domains and quality of life domains were analyzed using the Spearman rank correlation test. A p-value of less than 0.05 was considered statistically significant. All data analyses were performed using IBM SPSS Statistics version 22.

## Results

A total of 120 pre-elderly individuals living with HIV who sought treatment at healthcare facilities and participated in online-based HIV communities in Jakarta were included, with

**Table 1 Indonesian Version of WHOQOL-HIV BREF Questionnaire**

No	Question	Response Options (1-5)
1 (G1)	<i>Bagaimana Anda menilai kualitas hidup Anda?</i> (How would you rate your quality of life?)	1: Sangat buruk (Very poor), 2: Buruk (Poor), 3: Biasa saja (Neither poor nor good), 4: Baik (Good), 5: Sangat baik (Very good)
2 (G4)	<i>Seberapa puas Anda dengan kondisi kesehatan Anda?</i> (How satisfied are you with your health?)	1: Sangat tidak puas (Very dissatisfied), 2: Tidak puas (Dissatisfied), 3: Biasa saja (Neither satisfied nor dissatisfied), 4: Puas (Satisfied), 5: Sangat puas (Very satisfied)
3 (F1.4)	<i>Sejauh mana Anda merasa bahwa sakit fisik menghalangi Anda melakukan sesuatu pekerjaan? (To what extent do you feel that physical pain prevents you from doing what you need to do?)</i>	1: Sama sekali tidak (Not at all), 2: Sedikit (A little) 3: Cukup (A moderate amount), 4: Sangat (Very much), 5: Luar biasa (An extreme amount)
4 (F50.1)	<i>Seberapa banyak Anda merasa terganggu dengan masalah fisik yang terkait dengan infeksi HIV Anda?</i> (How much are you bothered by physical problems related to your HIV infection?)	1: Sama sekali tidak (Not at all), 2: Sedikit (A little) 3: Cukup (A moderate amount), 4: Sangat (Very much), 5: Luar biasa (An extreme amount)
5 (F11.3)	<i>Seberapa banyak Anda minum obat agar dapat menjalankan aktivitas sehari-hari? (How much do you rely on medical treatment to function in your daily life?)</i>	1: Sama sekali tidak (Not at all), 2: Sedikit (A little) 3: Cukup (A moderate amount), 4: Sangat (Very much), 5: Luar biasa (An extreme amount)
6 (F4.1)	<i>Seberapa jauh Anda menikmati hidup?</i> (To what extent do you enjoy life?)	1: Sama sekali tidak (Not at all), 2: Sedikit (A little) 3: Cukup (A moderate amount), 4: Sangat (Very much), 5: Luar biasa (An extreme amount)
7 (F24.2)	<i>Apakah Anda merasa hidup Anda berarti?</i> (To what extent do you feel your life is meaningful?)	1: Sama sekali tidak (Not at all), 2: Sedikit (A little) 3: Cukup (A moderate amount), 4: Sangat (Very much), 5: Luar biasa (An extreme amount)
8 (F52.2)	<i>Sejauh mana Anda terganggu oleh orang-orang yang menyalahkan Anda karena status HIV Anda? (To what extent are you bothered by people blaming you for your HIV status?)</i>	1: Sama sekali tidak (Not at all), 2: Sedikit (A little) 3: Cukup (A moderate amount), 4: Sangat (Very much), 5: Luar biasa (An extreme amount)
9 (F53.4)	<i>Seberapa takut Anda menghadapi masa depan?</i> (How much do you fear for the future?)	1: Sama sekali tidak (Not at all), 2: Sedikit (A little) 3: Cukup (A moderate amount), 4: Sangat (Very much), 5: Luar biasa (An extreme amount)
10 (F54.1)	<i>Seberapa khawatir Anda terhadap kematian?</i> (How much do you worry about death?)	1: Sama sekali tidak (Not at all), 2: Sedikit (A little) 3: Cukup (A moderate amount), 4: Sangat (Very much), 5: Luar biasa (An extreme amount)
11 (F5.3)	<i>Seberapa baik Anda mampu berkonsentrasi?</i> (How well are you able to concentrate?)	1. Sama sekali tidak (Not at all), 2: Sedikit (A little) 3: Cukup (A moderate amount), 4: Sangat (Very much), 5: Luar biasa (An extreme amount)
12 (F16.1)	<i>Seberapa amankah kehidupan sehari-hari yang Anda rasakan?</i> (How safe do you feel in your daily life?)	1: Sama sekali tidak (Not at all), 2: Sedikit (A little) 3: Cukup (A moderate amount), 4: Sangat (Very much), 5: Luar biasa (An extreme amount)
13 (F22.1)	<i>Seberapa sehat lingkungan fisik Anda?</i> (How healthy is your physical environment?)	1. Sama sekali tidak (Not at all), 2. Sedikit (A little), 3. Cukup (A moderate amount), 4. Sangat (Very much), 5. Luar biasa (An extreme amount)
14 (F2.1)	<i>Apakah Anda mempunyai cukup kekuatan untuk aktivitas sehari-hari? (Do you have enough energy for daily life?)</i>	1. Sama sekali tidak (Not at all), 2. Sedikit (A little), 3. Cukup (Moderately), 4. Sebagian besar (Mostly), 5. Sangat (Completely)
15 (F7.1)	<i>Apakah Anda merasa nyaman dengan penampilan fisik Anda?</i> (Are you able to accept your bodily appearance?)	1. Sama sekali tidak (Not at all), 2. Sedikit (A little), 3. Cukup (Moderately), 4. Sebagian besar (Mostly), 5. Sangat (Completely)
16 (F18.1)	<i>Apakah Anda mempunyai cukup uang untuk memenuhi kebutuhan Anda? (Do you have enough money to meet your needs?)</i>	1. Sama sekali tidak (Not at all), 2. Sedikit (A little), 3. Cukup (Moderately), 4. Sebagian besar (Mostly), 5. Sangat (Completely)
17 (F51.1)	<i>Apakah Anda merasa diterima oleh orang-orang yang Anda kenal? (To what extent do you feel accepted by the people you know?)</i>	1. Sama sekali tidak (Not at all), 2. Sedikit (A little), 3. Cukup (Moderately), 4. Sebagian besar (Mostly), 5. Sangat (Completely)

## (Continued)

No	Question	Response Options (1-5)
18 (F20.1)	<i>Seberapa mencukupi informasi yang Anda butuhkan dalam kehidupan Anda dari hari ke hari? (How available is the information you need in your daily life?)</i>	1: Sama sekali tidak (Not at all), 2: Sedikit (A little), 3: Cukup (Moderately), 4: Sebagian besar (Mostly), 5: Sangat (Completely)
19 (F21.1)	<i>Seberapa besar kesempatan Anda untuk melakukan kegiatan-kegiatan santai? (To what extent do you have opportunities for leisure activities?)</i>	1: Sama sekali tidak (Not at all), 2: Sedikit (A little), 3: Cukup (Moderately), 4: Sebagian besar (Mostly), 5: Sangat (Completely)
20 (F9.1)	<i>Seberapa jauh Anda mampu untuk jalan-jalan? (How well are you able to get around?)</i>	1: Sangat buruk (Very poor) , 2: Buruk (Poor), 3: Biasa saja (Neither poor nor good), 4: Baik (Good), 5: Sangat baik (Very good)
21 (F3.3)	<i>Apakah tidur Anda puas? (How satisfied are you with your sleep?)</i>	1: Sangat tidak puas (Very dissatisfied), 2: Tidak puas (Dissatisfied), 3: Biasa saja (Neither satisfied nor dissatisfied), 4: Puas (Satisfied), 5: Sangat puas (Very satisfied)
22 (F10.3)	<i>Seberapa puas Anda dengan kemampuan Anda untuk melakukan aktivitas sehari-hari Anda? (How satisfied are you with your ability to perform daily activities?)</i>	1: Sangat tidak puas (Very dissatisfied), 2: Tidak puas (Dissatisfied), 3: Biasa saja (Neither satisfied nor dissatisfied), 4: Puas (Satisfied), 5: Sangat puas (Very satisfied)
23 (F12.4)	<i>Seberapa puas Anda dengan kemampuan Anda untuk bekerja? (How satisfied are you with your ability to work?)</i>	1: Sangat tidak puas (Very dissatisfied), 2: Tidak puas (Dissatisfied), 3: Biasa saja (Neither satisfied nor dissatisfied), 4: Puas (Satisfied), 5: Sangat puas (Very satisfied)
24 (F6.3)	<i>Seberapa puas Anda dengan diri Anda sendiri? (How satisfied are you with yourself?)</i>	1: Sangat tidak puas (Very dissatisfied), 2: Tidak puas (Dissatisfied), 3: Biasa saja (Neither satisfied nor dissatisfied), 4: Puas (Satisfied), 5: Sangat puas (Very satisfied)
25 (F13.3)	<i>Seberapa puas Anda dengan hubungan pribadi Anda? (How satisfied are you with your personal relationships?)</i>	1: Sangat tidak puas (Very dissatisfied), 2: Tidak puas (Dissatisfied), 3: Biasa saja (Neither satisfied nor dissatisfied), 4: Puas (Satisfied), 5: Sangat puas (Very satisfied)
26 (F15.3)	<i>Seberapa puas Anda dengan hubungan intim Anda? (How satisfied are you with your sex life?)</i>	1: Sangat tidak puas (Very dissatisfied), 2: Tidak puas (Dissatisfied), 3: Biasa saja (Neither satisfied nor dissatisfied), 4: Puas (Satisfied), 5: Sangat puas (Very satisfied)
27 (F14.4)	<i>Seberapa puas Anda dengan dukungan yang Anda dapatkan dari teman-teman Anda? (How satisfied are you with the support you get from your friends?)</i>	1: Sangat tidak puas (Very dissatisfied), 2: Tidak puas (Dissatisfied), 3: Biasa saja (Neither satisfied nor dissatisfied), 4: Puas (Satisfied), 5: Sangat puas (Very satisfied)
28 (F17.3)	<i>Seberapa puas Anda dengan kondisi tempat tinggal Anda? (How satisfied are you with your living conditions?)</i>	1: Sangat tidak puas (Very dissatisfied), 2: Tidak puas (Dissatisfied), 3: Biasa saja (Neither satisfied nor dissatisfied), 4: Puas (Satisfied), 5: Sangat puas (Very satisfied)
29 (F19.3)	<i>Seberapa puas Anda dengan akses Anda kepada layanan kesehatan? (How satisfied are you with your access to health services?)</i>	1: Sangat tidak puas (Very dissatisfied), 2: Tidak puas (Dissatisfied), 3: Biasa saja (Neither satisfied nor dissatisfied), 4: Puas (Satisfied), 5: Sangat puas (Very satisfied)
30 (F23.3)	<i>Seberapa puas Anda dengan aktivitas Anda yang melibatkan transportasi? (How satisfied are you with your transport?)</i>	1: Sangat tidak puas (Very dissatisfied), 2: Tidak puas (Dissatisfied), 3: Biasa saja (Neither satisfied nor dissatisfied), 4: Puas (Satisfied), 5: Sangat puas (Very satisfied)
31 (F8.1)	<i>Seberapa sering Anda merasa putus asa, sedih, gelisah atau depresi? (How often do you experience negative feelings such as sadness, anxiety, despair, or depression?)</i>	1: Tidak pernah (Never), 2: Jarang (Seldom), 3: Seringkali (Quite often), 4: Sangat sering (Very often), 5: Selalu (Always)

Note: The response scale varies depending on the nature of the question (perception, frequency, intensity, or capability)

**Table 2 Questionnaire to assess HIV stigma using Berger HIV Stigma Scale**

No	Question	Response Option			
		STS (SD)	TS (D)	S (A)	SS (SA)
1.	<i>Pada sebagian besar area kehidupan saya, tidak ada yang tahu bahwa saya mengidap HIV</i> (In most areas of my life, no one knows that I have HIV)				
2.	<i>Saya merasa bersalah karena mengidap HIV</i> (I feel guilty because I have HIV)				
3.	<i>Sikap orang lain terhadap HIV membuat saya merasa lebih buruk mengenai diri saya</i> (People's attitudes towards HIV make me feel worse about myself)				
4.	<i>Memberitahu orang lain bahwa saya mengidap HIV adalah sesuatu yang berisiko</i> (Telling others that I have HIV is risky)				
5.	<i>Orang dengan HIV kehilangan pekerjaan mereka jika atasan mereka tahu tentang status HIV mereka</i> (People with HIV lose their jobs when their employers find out)				
6.	<i>Saya berusaha keras merahasiakan status HIV saya</i> (I work hard to keep my HIV status a secret)				
7.	<i>Saya merasa saya tidak sebaik orang lain karena saya mengidap HIV</i> (I feel that I am not as good a person as others because I have HIV)				
8.	<i>Saya tidak pernah merasa malu karena mengidap HIV</i> (I never feel ashamed of having HIV)				
9.	<i>Orang dengan HIV diperlakukan seperti orang buangan</i> (People with HIV are treated like outcasts)				
10.	<i>Sebagian besar orang meyakini bahwa orang dengan HIV adalah kotor</i> (Most people believe that a person who has HIV is dirty)				
11.	<i>Lebih mudah menghindari pertemanan baru dengan seseorang daripada dibebani kekhawatiran harus memberitahunya bahwa saya mengidap HIV</i> (It is easier to avoid new friendships than to worry about telling someone that I have HIV)				
12.	<i>Mengidap HIV membuat saya merasa tidak bersih</i> (Having HIV makes me feel unclean)				
13.	<i>Sejak mengetahui saya mengidap HIV, saya merasa tersisih dan terisolasi dari masyarakat lainnya</i> (Since learning that I have HIV, I feel isolated and set apart from others)				
14.	<i>Sebagian besar orang berpikir bahwa orang dengan HIV menjijikkan</i> (Most people think that a person with HIV is disgusting)				
15.	<i>Mengidap HIV membuat saya merasa bahwa saya adalah orang yang buruk</i> (Having HIV makes me feel like I am a bad person)				
16.	<i>Sebagian besar orang dengan HIV ditolak ketika orang lain mengetahui statusnya</i> (Most people with HIV are rejected when others know their status)				
17.	<i>Saya sangat berhati-hati kepada siapa saya memberitahu bahwa saya mengidap HIV</i> (I am very careful about whom I tell that I have HIV)				
18.	<i>Beberapa orang yang mengetahui saya mengidap HIV semakin menjauhi saya</i> (Some people who know I have HIV have grown more distant)				
19.	<i>Sejak mengetahui saya mengidap HIV, saya khawatir orang-orang akan mendiskriminasi saya</i> (Since learning I have HIV, I worry that people will discriminate against me)				
20.	<i>Sebagian besar orang tidak nyaman berada di sekitar orang dengan HIV</i> (Most people feel uncomfortable being around someone with HIV)				
21.	<i>Saya tidak pernah merasa perlu menyembunyikan fakta bahwa saya mengidap HIV</i> (I never feel the need to hide the fact that I have HIV)				
22.	<i>Saya khawatir orang akan menghakimi saya ketika mereka tahu saya mengidap HIV</i> (I worry that people will judge me when they learn that I have HIV)				

**(Continued)**

No	Question	Response Option			
		STS (SD)	TS (D)	S (A)	SS (SA)
23.	<i>Adanya HIV dalam tubuh saya merupakan sesuatu yang menjijikkan bagi saya</i> (Having HIV in my body feels disgusting )				
24.	<i>Saya pernah merasa sakit hati dengan reaksi orang lain setelah mengetahui bahwa saya mengidap HIV</i> (I have been hurt by how people reacted after learning that I have HIV)				
25.	<i>Saya khawatir bahwa orang yang mengetahui saya mengidap HIV akan memberitahu orang lain</i> (I worry that people who know I have HIV will tell others )				
26.	<i>Saya menyesal telah memberitahu beberapa orang bahwa saya mengidap HIV</i> ( I regret having told some people that I have HIV)				
27.	<i>Pada prinsipnya, memberitahu orang lain bahwa saya mengidap HIV adalah sebuah kesalahan</i> (Generally, telling others that I have HIV has been a mistake)				
28.	<i>Beberapa orang menghindari menyentuh saya setelah mereka tahu bahwa saya mengidap HIV</i> (Some people avoid touching me once they know I have HIV )				
29.	<i>Orang-orang yang saya sayangi berhenti menghubungi saya setelah mereka tahu saya mengidap HIV</i> (People I care about have stopped contacting me after learning that I have HIV)				
30.	<i>Orang-orang memberitahu saya bahwa saya pantas mendapatkan HIV karena cara saya menjalani hidup</i> (People have told me that I deserve to have HIV because of how I lived my life).				
31.	<i>Beberapa orang yang dekat dengan saya takut orang lain akan menolak mereka jika terungkap bahwa saya mengidap HIV</i> (Some people close to me are afraid others will re-ject them if they find out that I have HIV).				
32.	<i>Orang-orang tidak mau saya berada di dekat anak-anak mereka ketika mereka tahu saya mengidap HIV</i> (People do not want me around their children once they know that I have HIV)				
33.	<i>Orang-orang mundur menjauhi saya saat mereka tahu saya mengidap HIV</i> (People have physically backed away from me when they learn that I have HIV)				
34.	<i>Beberapa orang bersikap seolah-olah mengidap HIV adalah karena kesalahan saya</i> (Some people act as though it is my fault that I have HIV )				
35.	<i>Saya berhenti bersosialisasi dengan beberapa orang karena reaksi mereka ketika mereka tahu saya mengidap HIV</i> (I have stopped socializing with some people because of their reactions to my HIV status)				
36.	<i>Saya telah kehilangan teman-teman karena memberitahu mereka bahwa saya mengidap HIV</i> ( I have lost friends after telling them that I have HIV ).				
37.	<i>Saya telah memberitahu orang-orang yang dekat dengan saya untuk merahasiakan fakta bahwa saya mengidap HIV</i> (I have asked people close to me to keep my HIV status a secret.)				
38.	<i>Orang-orang yang mengetahui saya mengidap HIV cenderung mengabaikan sisi baik saya</i> (People who know that I have HIV tend to overlook my good qualities.)				
39.	<i>Orang-orang tampaknya takut kepada saya ketika mereka tahu saya mengidap HIV</i> (People seem afraid of me once they know that I have HIV.)				
40.	<i>Ketika orang-orang tahu Anda mengidap HIV, mereka mencari kelemahan pada karakter Anda</i> (When people find out that you have HIV, they look for flaws in your character.).				

Note: STS= Sangat tidak setuju SD= Strongly disagree, TS= Tidak setuju, D= Disagree , S= Setuju, A= Agree, SS= Sangat setuju, SA= Strongly agree

**Table 3 Characteristics of Pre-elderly Living with HIV in Jakarta, Indonesia (n=120)**

Variable	n (%)
Age, median (IQR) years	46 (IQR=4)
Gender	
Male	75 (62.5)
Female	43 (35.8)
Transgender	2 (1.7)
Education level	
Primary school	4 (3.3)
Junior high school	5 (4.2)
Senior high school	66 (55.0)
Associate/ Bachelor	40 (33.3)
Master/Doctoral	5 (4.2)
Marital status	
Unmarried	36 (30.0)
Married	49 (48.0)
Divorced	35 (29.2)
Monthly income	
< Provincial Minimum Wage	94 (78.3)
≥ Provincial Minimum Wage	26 (21.7)
Employment status	
Unemployed	44 (36.7)
Employed	76 (63.3)
Domicile	
East Jakarta	32 (26.7)
North Jakarta	10 (8.3)
West Jakarta	16 (13.3)
South Jakarta	37 (30.8)
Central Jakarta	23 (19.2)
Thousand Islands	2 (1.7)

the median age was 46 years (range of 45–59 years). The majority of respondents were male (62.5%), had graduated from senior high school (55%), were married (48%), employed (63.3%), had an income below the Provincial Minimum Wage (78.3%), and were domiciled in South Jakarta (30.8%) (Table 3).

Among the four stigma domains, two domains (personalized stigma and negative self-image) were normally distributed. The highest median stigma score was found in the public attitudes domain (median=41), followed by the personalized stigma domain (median=36).

All six quality of life domains showed a normal distribution ( $p>0.05$ ) with the highest median scores were observed in the physical domain (median=15), followed by the spiritual domain (median=15), indicating better perceived well-being in these aspects (Table 4).

The correlation analysis between stigma domains and quality of life domains indicated

a negative correlation between personalized stigma and disclosure concerns with the physical, psychological, independence, and spiritual domains. Additionally, the public attitudes domain was negatively correlated with physical, psychological, independence, environmental, and spiritual domains. The negative self-image domain showed a negative correlation with all quality of life domains ( $p<0.05$ ). Notably, a strong negative correlation was observed between the negative self-image domain and spiritual domain ( $r_s=-0.61$ ) (Table 5).

## Discussion

This study examined the relationship between HIV-related stigma and quality of life among pre-elderly individuals living with HIV in Jakarta. The analysis focused on how various domains of stigma correlate with different aspects of quality of life. In addition, it presented a descriptive overview of respondent characteristics.

The respondents characteristics in this study align with previous studies regarding gender and education level.<sup>13,14</sup> Most respondents were employed despite having low monthly income. This could be due to many working in non-governmental organizations (NGOs) related to HIV/AIDS or in micro-enterprises. Occupational type significantly influences income, with those in lower-level positions often earning below the provincial minimum wage.

The results of this study indicate that most stigma domains are significantly negatively correlated with quality of life domains. The dominant stigma domain was public attitudes. This might be influenced by persistent

**Table 4 Stigma and Quality of Life of Pre-elderly Living with HIV in Jakarta, Indonesia**

Variable	Median (IQR)
Stigma domain score	
Personalized stigma	36.00 (22)
Disclosure concerns	25.00 (10)
Public attitudes	41.00 (21)
Negative self-image	26.00 (13)
Quality of Life domain score	
Physical	15.00 (5)
Psychological	13.60 (4.0)
Independence	14.00 (4)
Social	13.00 (5)
Environmental	13.00 (4.4)
Spiritual	15.00 (6)

**Table 5 Correlation between Stigma Domains and Quality of Life among Pre-elderly Living with HIV**

Stigma	Quality of Life (rs)					
	Physical	Psychological	Independence	Social	Environmental	Spiritual
Personalized stigma	-0,30**	-0,33**	-0,21*	-0,14	-0,16	-0,49**
Disclosure concerns	-0,31**	-0,31**	-0,18*	-0,13	-0,13	-0,44**
Public attitudes	-0,32**	-0,38**	-0,23**	-0,17	-0,19*	-0,52**
Negative self-image	-0,46**	-0,49**	-0,36**	-0,33**	-0,34**	-0,60**

Note: Note \*p<0,05, \*\*p<0,001

misinformation, lack of public awareness regarding HIV/AIDS, and negative community perceptions toward PLWHIV.<sup>8</sup>

In contrast, the highest quality of life scores were observed in the physical and spiritual domains. Physically, PLWHIV who are adherent to antiretroviral therapy (ART) and have no comorbidities tend to experience better health outcomes.<sup>15</sup> The elevated spiritual well-being could be linked to cultural influences, personal acceptance, and spiritual reflection, where many PLWHIV find solace in religion as a means of coping.<sup>16</sup>

Interestingly, a significant negative correlation was found between personalized stigma and the physical, psychological, independence, and spiritual domains, showing that higher levels of personalized stigma were associated with diminished quality of life in these areas. Previous study suggests that greater personalized stigma may be linked to poorer HIV viral suppression.<sup>17</sup> However, the mechanisms remain unclear, but stigma can increase psychological stress, which undermines health outcomes. Fear of rejection often contributes to feeling of isolation, affecting independence.<sup>17-19</sup> Spiritually, PLWHIV with high level of personalized stigma may struggle with self-acceptance, feeling distant from spiritual support or perceiving their diagnosis as a form of divine punishment.<sup>16</sup>

Similarly, disclosure concerns were negatively correlated with the physical, psychological, independence, and spiritual domains. Fear of disclosing HIV status, often driven by the stigma of HIV being seen as a moral failing or a curse,<sup>20</sup> exacerbates mental distress, impedes treatment adherence, and diminished physical health.<sup>21,22</sup> Concealing PLWHIV's status often leads to social withdrawal and limits independence.<sup>22-24</sup> Additionally, fear of judgement can undermine spiritual well-being fostering feelings of blame toward oneself or toward a higher power.<sup>23</sup>

The public attitudes domain also showed

negative correlations with the physical, psychological, independence, environmental, and spiritual domains. Negative public reactions such as refusing to buy goods from PLWHIV, excluding them from social setting, or discriminating against their children, can severely impact both mental and physical health.<sup>8,25,26</sup> Societal rejection leads to delay in seeking care, loss of income due to employment discrimination, and reduced community participation. Furthermore, this rejection can also reduce level of spirituality, because some PLWHIV believe social stigma as a form of God's punishment.<sup>16</sup>

The most widespread negative impact was observed in the negative self-image domain, which was significantly correlated with reductions across all quality of life domains. Shame and self-stigmatization are especially pronounced among pre-elderly diagnosed with HIV, who may perceive themselves as "too old" to have HIV, compounding feeling of shame.<sup>10,27</sup> This shame leads to missed clinic appointments, reduced ART adherence, and worsening immune function, as reflected in CD4 cell count decline.<sup>28</sup> In addition, self-perceptions of being unworthy of love or support can cause deep psychological harm, including stress, depression, and withdrawal from social interactions.<sup>19</sup> Negative self-image also diminishes spiritual well-being, as individuals may view themselves as being punished by God, which hinders spiritual resilience.<sup>29</sup>

This study primarily focuses on the significant temporal correlation between stigma and quality of life among pre-elderly with HIV. However, further longitudinal study is needed to determine causality. Moreover, other factors such as the duration of HIV infection and the presence of comorbidities among PLWHIV should be considered. A longer duration of infection may affect greater psychological adaptation and better quality of life, whereas comorbidities may worsen health outcomes.<sup>30</sup> Conducting multivariable analysis

would provide deeper insights into how these factors impact stigma and quality of life of pre-elderly with HIV.

The limitation of the study is the limited number of variables and respondents, which may affect the generalizability of the result. Future study should include larger sample sizes and a more diverse set of variables. Qualitative studies, such as in-depth interviews, could further explore specific correlation, particularly between personalized stigma and spiritual well-being, disclosure concerns and spiritual well-being, and public attitudes and physical health.

In conclusions, there is a significant negative correlation between HIV-related stigma and quality of life across various domains among pre-elderly individuals living with HIV. Improving public understanding of HIV/AIDS is essential to reducing stigma. Targeted education for communities and families, including the development of culturally approach modules, may help reduce stigma and improve the quality of life for this population. Further research is needed to monitor how stigma continues to affect the well-being of pre-elderly PLWHIV and to develop effective interventions.

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