

Development of Self Stigma Assessment Tool for People Living With HIV/AIDS (PLWHA)

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ABSTRACT

Introduction: Stigma does not only come from people who give negative judgment to HIV/AIDS patients but also from patients themselves. This study explored the experiences of the self-stigma of people living with HIV/AIDS (PLWHA) and developed the self-stigma tool for PLWHA.

Methodology: We conducted a mixed-method study using an exploratory-sequential design in the East Java community, Indonesia. In the first phase, we identified 12 PLWHA through snowball sampling, and in the second phase, 133 PLWHA participated. We collected data through in-depth interviews. Subsequently, the insights gained from these interviews were utilized to develop a tool for assessing self-stigma among PLWHA, known as the MARSUDI self-stigma tool.

Results: The first phase of the study revealed three main themes: 1) the feeling of self-stigma, 2) the coping mechanism, and 3) suggestions to combat the stigma. Moving on to the second phase, the MARSUDI self-stigma tool for PLWHA was developed. This tool comprises 26 items, achieving a s-cvi score exceeding 0.80. Following factorial analysis, 20 items remained with a loading factor surpassing 0.6, and contributing to 66.24% of the total variance. These items were categorized into three factors: Factor 1 (self-perception) includes 7 items, Factor 2 (self-labelling) consists of 11 items, and Factor 3 (self-discrimination) comprises 2 items.

Conclusion: The results of this study revealed that the MARSUDI self-stigma of PLWHA is valid, reliable, and acceptable.

Keywords: Assessment Tool, Self-Stigma, People Living With HIV/AIDS

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INTRODUCTION

Control measures for HIV/AIDS still become the main interest in the health sector, and stigma and discrimination are the main challenges in HIV/AIDS prevention program management.¹ The consequence is the refusal of healthcare services, low adherence to antiretroviral therapy, and thus poorer treatment outcomes.^{2,3} Another negative impact of stigma and discrimination on PLWHA patients is a decrease in the patient's quality of life caused by strong psychological pressure such as stress, shame, and depression.^{4,5} Stigma and discrimination can originate from society, healthcare workers, family, and even the patients themselves.⁶ Support from family, religious leaders, healthcare workers, and counsellors is part of the psychological, spiritual, and social support in building coping mechanisms for PLWHA or their families.⁷ The result of this social support is that PLWHA will live far from the feeling of fear and be able to live as part of normal society. Psychosocial support also helps in reducing stigma and several negative consequences of being HIV-positive.^{8,9}

Research about the psychosocial status of HIV-positive people shows that living with HIV is tied to a huge amount of stress and depression.¹⁰ People living with HIV/AIDS also need to manage stigma related to HIV/AIDS, in addition to tolerating treatment with damaging side effects, dealing with refusal and social discrimination, and dealing with the deaths of other people as part of their social networking.¹¹ Being HIV-positive in general makes HIV part of one's identity; this will ingrain harmful self-stigma. Stigma to oneself also needs to be resolved soon, because although society no longer stigmatizes, if the patient still has a stigma to themselves, intervention failure will always happen.¹²

In Indonesia, there's currently no assessment tool tailored to identify self-stigma in HIV/AIDS patients that aligns with Indonesian characteristics and culture. The existing tools are mostly based on research from overseas, and they may not fully resonate with the unique characteristics and cultural context in Indonesia. To bridge this gap, our research employed an exploratory-sequential mixed method design. We delved into the self-stigma experienced by HIV/AIDS patients through in-depth interviews and subsequently utilized these insights to craft a culturally relevant tool specific to the self-stigma experienced by PLWHA, referred to as the "MARSUDI Self-Stigma Tool." This research aims to enhance the quality of life for PLWHA by actively engaging them in HIV/AIDS intervention programs. By addressing internalized stigma, we aspire to empower individuals to openly embrace their HIV-positive status.

METHODOLOGY

Research Design: The researcher employed a two-phase exploratory-sequential mixed-method design.

In the initial phase, the study delved into the qualitative exploration of the experiences of PLWHA regarding self-stigma. This phase aimed to fill gaps in our understanding of self-stigma aspects. The subsequent phase employed a quantitative approach, utilizing the findings from the qualitative phase. The MARSUDI self-stigma of PLWHA was developed and validated based on these results.

Population and Sample: The researcher established specific criteria for selecting participants in different phases of the study. In the qualitative phase, potential participants, identified as PLWHA, were required to meet the following conditions: 1) willingness to be informants; 2) residence in the Blitar region; and 3) a demonstration of interest in contributing by sharing their experiences during the interview. Purposive sampling through the snowball technique was employed for participant selection. Moving on to phase 2 of the study, which involved PLWHA in Indonesia, the criteria were as follows: 1) individuals who had not been interviewed during the qualitative phase; 2) those who provided informed consent; and 3) individuals capable of reading and understanding the questionnaire or tool written in the Indonesian language. In the qualitative phase, a total of 12 PLWHA met the established criteria, while in the quantitative phase, 133 PLWHA were involved for factorial analysis, along with 3 experts who participated in the content validity test.

Instrument: This study employed three instruments for data collection: in-depth interviews (using an interview guide) with PLWHA, observation sheets/field notes, and a self-stigma assessment tool specifically designed for PLWHA.

Data Collection Procedure: The researcher obtained ethical approval from the Health Polytechnic Ministry of Health in Malang, Indonesia, along with permits from the Head of Bakesbangpolinmas and the Health Agency of Blitar City and Blitar Regency. To gather data through qualitative methods, in-depth interviews were conducted with HIV/AIDS patients. These interviews took place at agreed-upon locations, lasting approximately 20-30 minutes, and were recorded. Some participants preferred interviews outside their homes to keep their HIV status confidential from their families. To ensure data accuracy, interview transcripts were created immediately after each session. Additionally, nonverbal responses from participants were documented as supplementary information in the field notes.

In this research, the data collection process can be summarized as follows: First step was to analyse the product to be developed through a literature review and interviews with PLWHA to understand their needs. The goal was to create a self-stigma assessment tool. This involved identifying current stigma through in-depth interviews with HIV/AIDS patients and further exploring relevant literature.

In subsequent step, the findings from in-depth interviews were analyzed using qualitative methods and

then integrated with the results from the literature review of the current assessment tool, forming the initial output.

After creating the product, experts assessed and validated it through field tests and evaluations. The trial phase involved 133 respondents. This was followed by socialization, product revision, dissemination and recommendation

Data Analysis: In the qualitative data coding process, we utilized software opencode as a tool. Following this, a validity test was conducted to identify the items in the assessment tool. To validate the assessment tool, an expert was invited to determine the Item – Content Validity Index (I-CVI) and Scale – Content Validity Index (S-CVI). The expert assessed each item's relevance to the underlying constructs on a scale of 1 – 4, where 1 means not relevant, 2 indicates that relevance cannot be assessed without item revision, 3 suggests relevance with minor revision needed, and 4 signifies very relevant. Lynn recommends I-CVI > 0.78 and S-CVI > 0.80 for validation.¹³ Next, we employed Cronbach's alpha to assess internal consistency. Additionally, exploratory factor analysis was conducted to reduce the dimensionality of the original space and provide an interpretation of the new space. This space is defined by a reduced number of dimensions, which are assumed to underlie the original ones. A total of 133 respondents were required for this test.

Ethical Approval: Before gathering data, the researchers ensured the protection of informants' rights through an agreement. This involved informing them that interview sessions would be recorded. The researchers directly communicated the research's purpose and benefits to the subjects, explaining their role in the research process. The recruitment process involved direct engagement by the researchers with candidates meeting the requirements, aided by PLWHA actively involved in AIDS prevention commission activities (local residents concerned about AIDS) and members of peer support groups. All information regarding the research subject's identity and responses was treated with utmost confidentiality. During the interviews, no informant withdrew, and the sessions proceeded smoothly, partly because some informants were interviewed directly by other PLWHA. The researchers concluded each interview by expressing gratitude through souvenirs and offering moral support to boost the informants' spirits, encouraging their continued participation in programs and fostering commitment to supporting government initiatives on HIV/AIDS prevention.

RESULTS

Phase 1 (Qualitative Phase)

Characteristics of The Participants: Based on the information in Table 1 with a sample size of 12 participants,

the age range spans from late teenage years to late adulthood. The youngest participant is 20 years old, while the oldest is 46. This data suggests that teenagers are also susceptible to HIV, as highlighted in the Basic Health Research and the 2020 report from the Blitar Health Agency, which indicated a rising incidence of HIV among teenagers. In response, the Blitar city government has been actively promoting awareness about HIV/AIDS in schools and youth organizations. The majority of participants are male, with only 2 females.

Table 1: Participant's Characteristics in March-November 2021 in Blitar City (N=12)

Characteristic	Participants (%)
Age	
15 – 25-Year-Old (Late Teenager)	3 (25)
26 – 35-Year-Old (Early Adult)	4 (33.3)
36 – 45-Year-Old (Late Adult)	5 (41.7)
Sex	
Male	10 (83.3)
Female	2 (16.7)
Educational Level of Respondent:	
High School	9 (75)
Bachelor's Degree	3 (25)
The Religion of Respondent:	
Islam	9 (75)
Catholic	2 (16.7)
Christian	1 (8.3)
Respondent's profession:	
Merchant	4 (33.3)
Self-employed kds	5 (41.7)
NGO	2 (16.7)
Karaoke hostess	1 (8.3)
Marriage status:	
Married	2 (16.7)
Single	8 (66.7)
Divorced/widow women	2 (16.7)

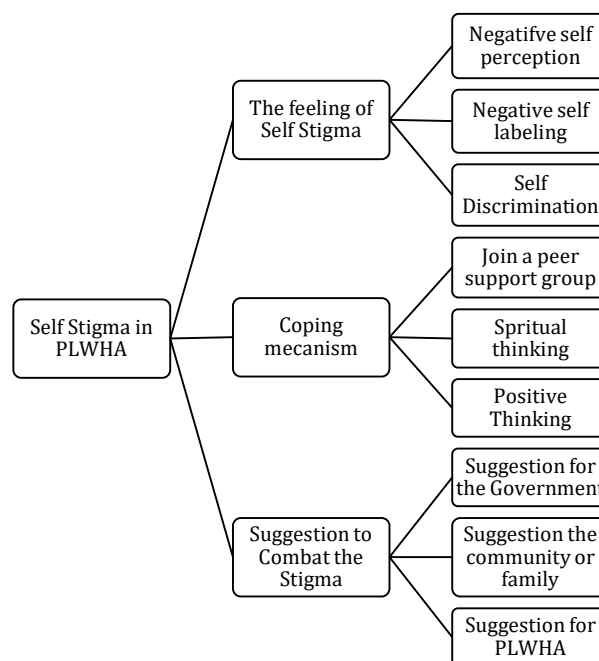


Figure 1: Themes of Self-Stigma In PLWHA

It's worth noting that these female participants were willingly interviewed and may not be representative of the overall gender distribution among HIV/AIDS patients. In terms of education, 9 participants have completed high school, while the rest have a college-level education. None of the participants lack education or have low educational attainment, indicating a generally mid to high-level education. Despite their decent knowledge of HIV/AIDS, the fact that they are still infected suggests the presence of other factors, such as behavior or other considerations, that need to be taken into account.

Most of the participants in this study follow the Islamic faith and are engaged in occupations such as merchants, self-employment, or work within organizations related to HIV management or volunteering. Interestingly, one participant shared that they work as a karaoke hostess. Additionally, it's noteworthy that a significant number of interviewees revealed that they have not yet entered into marriage.

The themes that emerged in phase 1: According to the findings presented in Figure 1, derived from phase 1 of the research, three main themes emerge. These are: 1) the experience of self-stigma, encompassing subthemes such as negative self-perception, negative self-labelling, and self-discrimination; 2) coping mechanisms, including subthemes like engaging in peer support groups, adopting spiritual thinking, and embracing positive thinking; and 3) recommendations for combating stigma, which include suggestions from the government, community, family, and PLWHA.

The process of developing a self-stigma assessment tool focused specifically on themes related to the feelings of self-stigma. This involved thorough discussions and revisions in collaboration with People Living with HIV/AIDS (PLWHA) and an expert team. Together, they carefully went through each of the 28 items/ statements, reaching a mutual agreement. To ensure the tool's validity, a team of three experts was involved, consisting of professionals from the Blitar City department managing HIV/AIDS cases, an HIV/AIDS counselor, and a nursing science doctorate specializing in HIV/AIDS and assessment instrument development. Validation of the instrument was conducted using the Content Validity Index (CVI), employing a scale with the following measurements: 1 for "Not Relevant," 2 for "Cannot Assess Relevance Without Item Revision," 3 for "Relevant but Needs Minor Revision," and 4 for "Very Relevant."

The assessment of each item (Individual CVI/I-CVI) is based on the number of experts providing positive evaluations (rated 3 and 4) versus irrelevant assessments (rated 1 and 2). This ratio is then divided by the total number of experts involved.¹⁴

Table 2 displays the Content Validity Index (CVI) for 28 items. Following a thorough evaluation by experts and the compilation of all responses and comments, only 26 items are proposed (see Table 3). Two items were excluded because their I-CVI fell below 0.78, and certain items were revised based on expert recommendations. It's important to note that an I-CVI score greater than 0.78 and an S-CVI exceeding 0.80 indicate the validity of the items. (13).

Table 2: Content Validity Index

Number	Statement	Expert 1	Expert 2	Expert 3	Total	Score I-CVI
1	I will certainly die	3	3	3	3	1,00
2	I am a disgrace to my family	4	4	4	3	1,00
3	I am a bad person	3	3	3	3	1,00
4	I am an embarrassment	4	3	3	3	1,00
5	I am disgusting	4	4	4	3	1,00
6	I am scary	4	4	3	3	1,00
7	My actions are sinful	3	3	3	3	1,00
8	I am forever disabled	4	3	4	3	1,00
9	I am often alone	4	3	4	3	1,00
10	My family is also being ostracized	4	3	3	3	1,00
11	I am afraid of being ostracized	4	4	3	3	1,00
12	I feel that people avoid me	3	3	4	3	1,00
13	I am afraid that my family will kick me out	4	3	4	3	1,00
14	I am afraid of having relationships with others	3	4	3	3	1,00
15	I am embarrassed to meet other people	4	3	4	3	1,00
16	I want to kill myself	1	2	3	1	0,33
17	They don't respect me	3	3	4	3	1,00
18	My illness is shameful	4	4	3	3	1,00
19	I feel that I am a burden	4	4	4	3	1,00
20	I am afraid that my future will be destroyed	3	4	4	3	1,00
21	I am afraid that I can't marry someone	4	4	4	3	1,00
22	I feel that I made my family feel ashamed	4	4	4	3	1,00
23	I feel that I disappointed my parents	4	4	3	3	1,00
24	I feel worthless	4	4	4	3	1,00
25	My eating utensils are set aside	3	3	3	3	1,00
26	My toiletries are set aside	3	3	3	3	1,00
27	I was rejected when applying for work	4	4	4	3	1,00
28	People distanced themselves because I am HIV positive	1	1	3	1	0,33

Table 3: Revised Items and Removed Items based on Expert's Team

Number	Initial Statement	Revision Result
1	I will certainly die	My sickness cannot be cured
2	I am a disgrace to my family	I bring disgrace
7	My actions are sinful	I am a sinful person
8	I am forever disabled	I will be forever disabled
9	I am often alone	I feel lonely
16	I want to kill myself	Removed
25	My eating utensils are set aside	My eating utensils are set aside
26	My toiletries are set aside	My toiletries are set aside
27	I was rejected when applying for work	I will not be accepted if I apply for work
28	People distanced themselves because I am HIV positive	Removed

Phase 2 (Quantitative Phase / Assessment Tool Trial)

Characteristics of The Participants: According to Table 4, about 20.3% of respondents fall into the late teenager category, while 3.0% are classified as early elderly. The majority of participants are male, with females making up approximately 29.3%. In terms of educational level, 85% have completed high school or above, and none reported having no education. The prevalent religion among participants is Islam. Professions vary, with 3.8% identified as CSWs, and others engaged in occupations like starting a hairdresser, serving as HIV cadres, managing KDS (peer support group member), etc. Notably, 17.3% of participants are currently unemployed. Interestingly, over half of the respondents (63.9%) are not married, and despite being at an age conducive to marriage, only 18.8% are married. A significant portion of participants (78.2%) acknowledges the importance of socializing with others and expresses this by actively participating in community organizations.

Exploratory Factorial Analysis (EFA): EFA is employed to gather information from exploration and relationships among a set of variables. Its goal is to consolidate correlated variables into a fundamental variable or category.

The factor analysis yielded a KMO value of 0.926 and a Bartlett's test value of 2980, indicating a p-value of 0.000. This is noteworthy as a KMO value above 0.6 is considered essential for a reliable factor analysis.¹⁵ These results suggest that the variables are suitable for further analysis using factor analysis. Subsequent analysis was conducted, and the findings are presented in Table 6 below.

Table 5 indicates that there are three initial eigenvalues with a score greater than 1.00. This suggests that the findings or items in the questionnaire should be categorized into a three-factor group or domain. The cumulative percentage is 66.237, signifying that the research results can account for 66.237% of the considered factors. To determine the loading factor, the research team set a threshold of >0.6 for self-stigma items. Out of the 26 items, 20 have a loading factor exceeding 0.6. According to the Exploratory Factor Analysis (EFA) results presented in Table 6, these items are distributed among three factors.

Table 4: Characteristics of Respondent in Phase 2, March-November 2021 in Blitar City (N=133)

Characteristic	Respondent (%)
Age	
17 - 25-Year-Old (Late Teenager)	27 (20.3)
26 - 35-Year-Old (Early Adult)	73 (54.9)
36 - 45-Year-Old (Late Adult)	29 (21.8)
46 - 55-Year-Old (Early Elderly)	4 (3.0)
Sex	
Male	94 (70.7)
Female	39 (29.3)
Educational Level of Respondent	
Elementary School	5 (3.8)
Middle School	15 (11.3)
High School	92 (69.2)
Bachelor's Degree	21 (15.8)
The Religion of Respondent	
Islam	121 (91)
Hindu	1 (0.8)
Christian	6 (4.5)
Buddha	5 (3.8)
Respondent's Profession	
Self-Employed	46 (34.6)
HIV Cadres/KDS	5 (3.8)
Instructor Course & Training Institution	28 (21.1)
CSW (Commercial Sex Worker)	5 (3.8)
Merchant	8 (6.0)
Labor Worker	11 (8.3)
Unemployed	23 (17.3)
Teacher	2 (1.5)
College Student	3 (2.3)
Hairdresser	2 (1.5)
Marriage Status	
Married	25 (18.8)
Single	85 (63.9)
Divorced/Widow Woman	18 (13.5)
Divorced/Widow Man	5 (3.8)
Community Organization	
KDS	57 (42.9)
NGO	42 (31.6)
Others	5 (3.8)
Nothing	29 (21.8)

Table 5: KMO and Bartlett's Test Value

Kaiser-Meyer-Olkin Measure of Sampling Adequacy	
.926	
Bartlett's test of sphericity	
Approx. Chi-Square	2980.225
Df	325
P-Value	0.000

Table 6: Items Based on Loading Factor >6

Latest Number of Items	Initial Number of Items	Statement	Factor 1	Factor 2	Factor 3
1	11	I am afraid of being ostracized	0.715		
2	13	I am afraid that my family will kick me out	0.693		
3	14	I am afraid of having relationships with others	0.709		
4	15	I am embarrassed to meet other people	0.635		
5	16	I feel I am not respected as a person	0.635		
6	17	I am embarrassed by my illness	0.777		
7	18	I feel that I am a burden	0.639		
8	19	I am afraid that my future will be destroyed	0.782		
9	20	I am afraid that I can't marry someone	0.677		
10	21	I feel that I made my family feel ashamed	0.840		
11	22	I feel that I disappointed my parents	0.762		
12	1	I feel I will die at a young age		0.615	
13	4	I am an embarrassment		0.760	
14	5	I am disgusting		0.842	
15	6	I am scary		0.737	
16	8	I will be forever disabled		0.634	
17	10	My family is also being ostracized		0.698	
18	12	I feel that people avoid me		0.623	
19	24	My eating utensils are set aside			0.909
20	25	My toiletries are set aside			0.918

Notes: Factor 1 Negative Self-Perception; Factor 2 Negative Self-Labeling; Faktor 3 Self Discrimination

Table 7: List of 20 Items based on Loading Factor, Validity Test, and Reliability

Statement	Validity (Person Product Moment)	Reliability (Cronbach's Alpha)
Factor 1: Negative Self-Perception		0.960
1 I am afraid of being ostracized	0.000	
2 I am afraid my family will kick me out	0.000	
3 I am afraid of having relationships with others	0.000	
4 I am embarrassed to meet other people	0.000	
5 I feel I am not respected as a person	0.000	
6 I am embarrassed by my illness	0.000	
7 I feel that I am a burden	0.000	
8 I am afraid that my future will be destroyed	0.000	
9 I am afraid that I can't marry someone	0.000	
10 I feel that I made my family feel ashamed	0.000	
11 I feel that I disappointed my parents	0.000	
Factor 2: Negative self-labeling		0.937
12 I feel I will die at a young age	0.000	
13 I am an embarrassment	0.000	
14 I am disgusting	0.000	
15 I am scary	0.000	
16 I will be forever disabled	0.000	
17 My family is also being ostracized	0.000	
18 I feel that people avoid me	0.000	
Factor 3: Self discrimination		0.975
19 My eating utensils are set aside	0.000	
20 My toiletries are set aside	0.000	

Based on the table above, 20 items of the self-stigma questionnaire are valid and reliable.

DISCUSSION

In phase 1 of our research, we identified three significant themes. First and foremost is the theme of self-stigma, comprising three sub-themes: negative self-perception, negative self-labeling, and self-discrimination. This aligns with Rich et al.'s 2022 study, highlighting that negative self-perceptions associated with HIV can adversely affect the quality of life for patients.¹⁶ Stigmatizing HIV-positive individ-

uals may lead to feelings of depression, potentially sparking thoughts of suicide in affected patients.¹⁷ Stigma in HIV patients also causes low self-esteem, which can lead to a decline in the patient's psychological health. Therefore, PLWHA must be treated with respect and dignity so as not to reduce their psychological health.¹⁸

The coping mechanism includes various subthemes such as joining a peer support group, engaging in spiritual thinking, and fostering positive thoughts. A

recommended approach to enhance coping mechanisms among HIV patients facing negative stigma is through participation in peer support groups. This aligns with findings from Chime's 2019 research, which highlights the effectiveness of peer support groups in building social support for individuals with HIV dealing with negative stigma.¹⁹ Peer support plays a crucial role in enhancing the quality of life for PLWHA. This is achieved through consistent mutual support and the continual reinforcement of each other.²⁰ In addition to receiving support from peers, engaging in religious and spiritual practices can also help alleviate stigma for individuals living with HIV. By participating in activities related to religion and spirituality, people living with HIV/AIDS (PLWHA) can openly express their emotions through prayer, contributing to a sense of inner peace.²¹

Recommendations to address stigma include input from the government, community, and family, as well as people living with HIV/AIDS (PLWHA). Offering support within the family is a key approach to lessening stigma in PLWHA individuals. By fostering family support and promoting non-discrimination, we can enhance the quality of life for PLWHA. This involves assisting patients with adhering to antiretroviral therapy and diminishing the stigma surrounding HIV. Hence, there is a crucial need to amplify and fortify family support to ensure optimal care for those living with HIV.²² The government also plays a crucial role in minimizing the stigma surrounding HIV patients. One of its key responsibilities is to educate the public about HIV. By offering information and education within the community, the government can help alleviate the adverse effects experienced by patients. This proactive approach not only reduces stigma and discrimination but also challenges stereotypical prejudices by changing the community's attitude towards them.²³

CONCLUSION

This research explored three major themes. Firstly, self-stigma was explored, encompassing self-perception, self-labelling, and self-discrimination. Secondly, coping mechanisms were identified, including participation in community organizations, spiritual reflection, and adopting a positive mindset. Lastly, suggestions from PLWHA to combat self-stigma were directed towards themselves, society/family, and the government. In this study, the self-stigma assessment tool for PLWHA, known as the "MARSUDI Self-Stigma of PLWHA," consists of 20 items and was established as a valid and reliable measure.

Ethical Approval:

The ethical approval from the Research Health Ethical Committee of Poltekkes Kemenkes Malang Number 159/III/KEPK POLKESMA/2023 dated March 30, 2023.

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