

Relationship between stigma and health-related quality of life among people living with HIV

Silvia Farhanidiah¹, Nursalam Nursalam¹, Mira Triharini¹, Ferry Efendi¹, Rr Dian Tristiana¹, Diah Priyantini², Rio Ady Erwansyah¹, Misutarno Misutarno³

¹Universitas Airlangga, Jawa, Indonesia

²Universitas Muhammadiyah Surabaya, Jawa, Indonesia

³Dr. Soetomo Teaching Hospital, Jawa, Indonesia

Abstract

Introduction: Human immunodeficiency virus (HIV)-related stigma is one of the several challenges which people living with HIV (PLWH) need to overcome. Society's stigma and discrimination prevent PLWH from seeking professional healthcare services, while feeling distressed, guilty, depressed, despairing, and disowned. This has an impact on their quality of life. This study aimed to analyze the relationship between stigma and health-related quality of life (HR-QoL) among PLWH.

Material and methods: Using purposive sampling and inclusion and exclusion criteria, hundred HIV-infected individuals were included. This study employed a cross-sectional study approach, and data collection was done with WHOQOL-HIV-BREF questionnaire. Data were analyzed using Spearman's rho test to identify the relationship between stigma and HR-QoL, with a p -value < 0.05 considered statistically significant. Descriptive statistics were employed to identify demographic characteristics of respondents.

Results: The results showed that there was a moderate positive relationship between stigma and depression symptoms ($p = 0.000$, $r = 0.5222$), and a weak positive relationship between stigma and physical functioning ($p = 0.021$, $r = 0.231$) and QoL ($p = 0.030$, $r = 0.217$). However, there was no correlation between HIV stigma and overall general health ($p = 0.371$, $r = 0.900$).

Conclusions: HIV-related stigma is associated with HR-QoL of PLWH. Respondents who experienced HIV stigma had severe depression symptoms, fair physical functioning, and fair overall general health, while most of the respondents did not have a good QoL. Family empowerment and social support are both affecting quality of life of PLWH, and are as important as medical support in influencing their life expectancy and self-esteem to accept living with the disease.

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Key words: AIDS, HIV, HIV stigma, HR-QoL, PLWH.

Introduction

Human immunodeficiency virus (HIV)/acquired immune deficiency syndrome (AIDS) is a major public health chal-

lenge, and remain one of the most stigmatized diseases globally, with 1.5 million new HIV cases in 2020. The Joint United Nations program on HIV/AIDS reported that over 50% of people have negative and discriminatory attitudes

Address for correspondence: Prof. Nursalam Nursalam, Universitas Airlangga, Jawa, Indonesia, e-mail: nursalamm@fkip.unair.ac.id

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towards those living with HIV. The perception that HIV is concentrated among key populations involving homosexuality, prostitution, and drug abuse, impairs HIV-related stigmatization. HIV stigma, various ways of discrimination, negative labelling, and discriminatory behaviors from society, including health workers, communities, and family, all lead to self-isolation, social exclusion, loss of job, economic difficulty, and poor access to healthcare services [1-4].

People living with HIV (PLWH) face many challenges in medical management of the disease. HIV-related stigma is rooted in fear of HIV; it has emerged as the first appearing HIV image in early 1980s, associated with prevailing misconceptions (e.g., ways of transmission) [5, 6]. HIV-related stigma and discrimination have been a significant barrier in accessing healthcare, hence, contributing to poor health outcomes (e.g., criticism, blaming, shouting at or throwing health records on patients, negligence, etc.) [1, 7]. HIV-related stigma and discrimination negatively influence PLWH's quality of life (QoL) by preventing them from seeking professional healthcare services, feeling distressed, guilty, depressed, despairing, and disowned. This became a major obstacle in HIV prevention and control [8]. A review by Rueda [9] reported that HIV-related stigma is associated with higher level of depression and lower level of social support. Moreover, both depression and social support were correlated, and HIV stigma was associated with poorer mental outcomes, such as emotional distress, shame, reduced self-esteem, decreased psychological functioning, poorer physical adjustment, negative effect, anxiety, suicidal ideation, life satisfaction, QoL, and stress associated with disclosure.

Since HIV/AIDS can develop into a chronic disease, QoL is a multi-dimensional concept that is recognized as a significant indicator used to assess health in various aspects of PLWH life [10]. HIV-related stigma is common among HIV-infected individuals, and associated with poor health-related QoL (HR-QoL). HIV stigma can take different forms, including anticipatory stigma, internalized stigma, and enacted stigma. Anticipatory stigma concerns individuals' expectations of facing enacted HIV-related stigma as a result of being HIV-positive. Enacted HIV-related stigma involves experiencing stigmatizing behaviors or negative treatment because of one's HIV status. Whereas internalized HIV-related stigma occurs when individuals adopt stigmatizing beliefs about PLWH, and apply these stigmatizing beliefs to themselves. In the framework of relationship between HIV-related stigma and health and well-being of PLWH [11], this cross-sectional study aimed to examine the HIV-related stigma effects on HR-QoL of PLWH, based on their depression symptoms, physical functioning, and overall general health.

Material and methods

Descriptive analytic with a cross-sectional approach was used in the current study. Sample collection employed non-probability sampling, with a purposive sampling tech-

nique. This study was conducted at Dr. Soetomo Hospital, among HIV-positive patients from June to November 2020. Inclusion criteria were literacy, HIV/AIDS diagnosis for at least 6 months, age above 20 years, and no psychiatric disorders. Exclusion criteria were hospitalized patients and those severely ill. Hundred individuals fulfilled the requirements. The dependent variable of this study was HR-QoL, and the independent variable was stigma.

Data collection was done by using a WHOQOL-HIV-BREF questionnaire in local language Bahasa, and a brief scale to measure stigma with total 39 questions. Collected data were analyzed using Spearman's rho test to identify the relationship between stigma and HR-QoL, with a *p*-value < 0.05 meaning the variable is related, while demographic characteristics of respondents were identified using descriptive statistics.

Ethical clearance

This research received ethical approval from the Research Ethics Committee at the Faculty of Nursing, Universitas Airlangga, Surabaya, with approval number of 2038-KEPK in 2020. The researchers respected the respondents' code of ethics by always maintaining honesty and confidentiality.

Results

Respondents' characteristics

Typical age distribution was 26-35 years (36.0%) and 36-45 years (36.0%), with majority of females (49.0%) and married (39.0%). Most of the patients' latest education level was elementary school (33.0%), and the majority were working as employees (53.0%), with monthly income under UMR (regional minimum wage) (71.0%) (Table 1). The study results showed that most of the participants had no opportunistic infection (87.0%) and were in generally good condition (98.0%). Most of the patients had been diagnosed with HIV for more than one year (68.0%), their first HIV test was done more than one month ago (78.0%), and were infected through sexual contact (88.0%) (Table 1).

Relationship between HIV stigma and HR-QoL in PLWH

HIV-related stigma and depression symptoms

The majority of respondents who experienced HIV stigma (7/12, 58.3%) had severe depression symptoms, and most of those who did not experience HIV stigma (55/88, 62.5%) had moderate depression symptoms. The results of statistical analysis using Spearman's rho test obtained *p*-value = 0.000 and *r*-value = 0.5222, meaning that there was a moderate positive relationship between stigma and depression symptoms. It was indicated that when HIV-related stigma increases, the depression tends to increase also (Table 2).

Table 1. Respondents' characteristics

Characteristics of respondents	n (%)
Age	
17-25 years	6 (6.0)
26-35 years	36 (36.0)
36-45 years	36 (36.0)
46-55 years	21 (21.0)
> 55 years	1 (1.0)
Sex	
Male	51 (51.0)
Female	49 (49.0)
Education	
Elementary school	33 (33.0)
Junior high school	16 (16.0)
Senior high school	28 (28.0)
Bachelor's degree	23 (23.0)
Marital status	
Single	19 (19.0)
Married	39 (39.0)
Widowed	33 (33.0)
Divorced	9 (9.0)
Employment	
Civil servant	0 (0.0)
Employe	53 (53.0)
Entrepreneur	10 (10.0)
Unemployed	37 (37.0)
Monthly income	
< UMR	71 (71.0)
> UMR	29 (29.0)
Opportunistic infection	
Yes	13 (13.0)
No	87 (87.0)
Health condition	
Good	98 (98.0)
Unwell	2 (2.0)
Sick	0 (0.0)
HIV diagnosis	
< 1 year	32 (32.0)
> 1 year	68 (68.0)
First HIV test	
< 1 month	22 (22.0)
> 1 month	78 (78.0)
Way of HIV transmission	
Sexual contact	88 (88.0)
Injecting drug user	9 (9.0)
Mother-to-child transmission	3 (3.0)

HIV-related stigma and physical functioning

Most of the respondents who experienced HIV stigma (9/12, 75.0%) and those who did not experience HIV stigma (67/88, 76.1%) had fair physical functioning, with Spearman's rho test showing p -value = 0.021 and r -value = 0.231, indicating a weak positive relationship between stigma and physical functioning. It was demonstrated that when HIV-related stigma increases, it impacts the physical functioning (Table 2).

HIV-related stigma and overall general health

The majority of patients who experienced HIV stigma (8/12, 66.7%) and those who did not experience HIV stigma, (45/88, 51.1%) had fair overall general health, with Spearman's rho test showing p -value = 0.371 and r -value = 0.900, indicating no correlation between HIV stigma and overall general health. As HIV-related stigma increases, there is no tendency influencing the overall general health (Table 2).

HIV-related stigma and QoL

Most of the participants who experienced HIV stigma (9/12, 75.0%) and those who did not experience HIV stigma (71/88, 80.7%) had a fair QoL, with Spearman's rho test showing p -value = 0.030 and r -value = 0.217, indicating a weak positive relationship between HIV stigma and QoL. It was demonstrated that when HIV-related stigma increases, it effects the QoL (Table 2).

Discussion

In Indonesia, HIV-related stigma among PLWH is still reported to be high, being a major problem in improving their QoL. HIV stigma occurs due to various views, perceiving HIV as a disease caused by immoral behaviors, which depart from social and religious values, while religion/spirituality promote adherence [10, 12, 13]. HIV patients on antiretroviral therapy (ART) who are living in urban areas were 4 times more likely to experience a better QoL as compared with HIV-infected individuals on ART living in rural areas [14]. In this research, most of the respondents were married, in generally good health condition, had been diagnosed with HIV for more than one year, and did not experience HIV stigma. A previous study has shown that being married or living with a partner as well as ART duration were associated with a decrease of HIV stigma. Marital status is beneficial in terms of perceived social and psychological support of PLWH with better acceptance [1]. Another study reported that PLWH who were married had a higher HIV-related stigma and discrimination as compared with those who were unmarried or widowed. It is because they were more likely to interact with people [15]. Furthermore, women living with HIV suffered greater stigma-related con-

Table 2. Relationship between stigma and health-related quality of life among people living with HIV

Variable	Stigma				Statistic test: Spearman rho	
	Experienced		Not experienced			
	n	%	n	%		
Depression symptoms						
Severe	7	58.3	12	13.6	$p = 0.000$ $r = 0.522$	
Moderate	4	33.3	55	62.5		
Mild	1	8.3	21	23.9		
Total	12	100.0	88	100.0		
Physical functioning						
Poor	3	25.0	7	8.0	$p = 0.021$ $r = 0.231$	
Fair	9	75.0	67	76.1		
Good	0	0.0	14	15.9		
Total	12	100.0	88	100.0		
Overall general health						
Poor	1	8.3	5	5.7	$p = 0.371$ $r = 0.900$	
Fair	8	66.7	45	51.1		
Good	3	25.0	38	43.2		
Total	12	100.0	88	100.0		
Quality of life						
Poor	3	25.0	10	11.4	$p = 0.030$ $r = 0.217$	
Fair	9	75.0	71	80.7		
Good	0	0.0	7	8.0		
Total	12	100.0	88	100.0		

sequences with multiple health outcomes when compared with men [16]. Individual belief influences QoL, because is connected with psychological aspects and demonstrating PLWH's point of view about the disease and related stigma. Social support, as moderating factor in the relationship between HIV stigma and depression, indicates the role of social support in buffering depressive symptoms among PLWH [9]. Social support and social capital affect the structural and cognitive dimensions of human health, improve mental health, and reduce the risk of common psychological disorders, such as depression and anxiety, by simultaneously affecting individuals and community [17]. It is difficult for PLWH to improve their QoL in community due to stigmatization that negatively influence their social support seeking [13]. Family empowerment and social support are as important as medical support. They influence HIV-infected patients' life expectancy and self-esteem to accept living with the disease, therefore, it impacts their QoL.

There are three types of HIV-related stigma, i.e., self-perceived stigma, internalized stigma, and experienced stigma, which commonly occur in three areas, such as social/community, medical, and health work. Self-perceived stigma (or personal perception) was found to more negatively impact the overall well-being among PLWH than external discrimination [1]. A previous study reported that perceived

public stigma and experienced stigma predicted higher self-stigma. The role of social support in perceived stigma affect self-stigma, where personal belief is important in self-esteem and self-care of PLWH. Self-care is related to HR-QoL, and determined by social factors, including stigma [18, 19]. Greater stigma is associated with reduced adherence to ART, and increased mental distress, such as depression, anxiety, hopelessness, and problems in receiving appropriate or suitable treatment. Additionally, stigma is impacting the structural issues, which made adherence difficult while routinization [5, 12]. A previous study reported that the perceived community stigma lead to internalized stigma, resulting in stigma anticipated from the community and associated with lower medication adherence [20].

HR-QoL is a multi-dimensional concept that includes domains related to physical, mental, emotional, and social functioning [21]. In the current study, the significant relationship between HIV-related stigma and HR-QoL showed that PLWH who experienced HIV stigma had severe depression symptoms, fair physical functioning, and most of the them did not have a good QoL. This is in line with a study done in China, where HIV stigma and public discrimination in PLWH have led them to feel guilty, having no normal interaction with their friends, no social support, and denied job opportunities. Deterioration of health may

disclose their treatment status and low self-esteem, resulting in poor QoL. Moreover, experiencing HIV stigma associated with ART influences PLWH's QoL [8, 22, 23]. HIV stigma was negatively correlated with HR-QoL among PLWH. The higher the stigma experienced by the patients, the lower the PLWH's QoL. However, the duration of treatment was not related to PLWH's QoL [16, 24, 25].

In this study, we used a generic HR-QoL questionnaire, and found no correlation between HIV-related stigma and overall general health. The present study demonstrated that HIV stigma negatively influence mental health status, while health status was directly and negatively associated with mental health. Social capital both directly and indirectly demonstrated the most significant and negative effect on mental health. Also, the duration of the disease indirectly showed the most significant and positive effect on mental health problems [17]. Another study reported significant association between the scale and overall health, depression and experience of stigma/discrimination [26]. However, generic HR-QoL measures might not be sensitive enough to investigate stigma, treatment adherence, or sexual health [27].

Study limitations

This study has two limitations; firstly, it provides results, which are representative of the Indonesian population. The results were validated using several samples and internationally recognized measurement tools. However, cross-sectional studies have a number of disadvantages, including the inability to estimate incidence and draw conclusions about causes. The second limitation is the study small sample size.

Conclusions

The results of this study showed that HIV-related stigma negatively impacts HR-QoL of PLWH. The participants who experienced HIV stigma had severe depression symptoms, fair physical functioning, and fair overall general health, while most of the respondents did not have a good QoL. To address this problem, future research should focus on investigating ways to reduce HIV-related stigma in society.

Disclosures

1. Institutional review board statement: This study was approved by the Research Ethics Committee at the Faculty of Nursing, Universitas Airlangga, Surabaya, with approval number of 2038-KEPK.
2. Assistance with the article: We would like to thank all the respondents and those who helped in the implementation of this study.
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4. Conflicts of interest: None.

References

1. Rayanakorn A, Ong-Artborirak P, Ademi Z, Chariyalertsak S. Predictors of stigma and health-related quality of life among people living with HIV in Northern Thailand. AIDS Patient Care STDS 2022; 36: 186-193.
2. Mahamboro DB, Fauk NK, Ward PR, Merry MS, Siri TA, Mwanri L. HIV stigma and moral judgement: qualitative exploration of the experiences of HIV stigma and discrimination among married men living with HIV in Yogyakarta. Int J Environ Res Public Health 2020; 17: 636. DOI: 10.3390/ijerph17020636.
3. CDC. Statistics overview: HIV surveillance report [Internet]. www.cdc.gov. 2022. International Statistics. Available from: <https://www.cdc.gov/hiv/statistics/overview/index.html> (Accessed: 04.10.2022).
4. Ulloa JD, Sherrel Z. What to know about HIV stigma and discrimination [Internet]. MEdical News Tiday. 2021. Available from: <https://www.medicalnewstoday.com/articles/hiv-stigma> (Accessed: 04.10.2022).
5. Rasoolinajad M, Abedinia N, Noorbala AA, Mohraz M, Badie BM, Hamad A, et al. Relationship among HIV-related stigma, mental health and quality of life for HIV-positive patients in Tehran. AIDS Behav 2018; 22: 3773-3782.
6. CDC. HIV stigma and discrimination [Internet]. Centers for Disease Control and Prevention. 2021. Available from: <https://www.cdc.gov/hiv/basics/hiv-stigma/index.html> (Accessed: 04.10.2022).
7. Fauk NK, Ward PR, Hawke K, Mwanri L. HIV stigma and discrimination: perspectives and personal experiences of healthcare providers in Yogyakarta and Belu, Indonesia. Front Med 2021; 8: 625787. DOI: 10.3389/fmed.2021.625787.
8. Wu X, Chen J, Huang H, Liu Z, Li X, Wang H. Perceived stigma, medical social support and quality of life among people living with HIV/AIDS in Hunan, China. Appl Nurs Res 2015; 28: 169-174.
9. Rueda S, Mitra S, Chen S, Gogolishvili D, Globerman J, Chambers L, et al. Examining the associations between HIV-related stigma and health outcomes in people living with HIV/AIDS: a series of meta-analyses. BMJ Open 2016; 6: e011453. DOI: 10.1136/bmjopen-2016-011453.
10. Desyani NLJ, Waluyo A, Yona S. The relationship between stigma, religiosity, and the quality of life of HIV-positive MSM in Medan, Indonesia. Enferm Clin 2019; 29: 510-514.
11. Parcesepe AM, Nash D, Tymejczyk O, Reidy W, Kulkarni SG, Elul B. Gender, HIV-related stigma, and health-related quality of life among adults enrolling in HIV care in Tanzania. AIDS Behav 2020; 24: 142-150.
12. Duthely LM, Sanchez-Covarrubias AP, Brown MR, Thomas TE, Montgomerie EK, Dale S, et al. Pills, PrEP, and pals: adherence, stigma, resilience, faith and the need to connect among minority women with HIV/AIDS in a US HIV epicenter. Front Public Health 2021; 9: 667331. DOI: 10.3389/fpubh.2021.667331.
13. Erwansyah RA, Rumambo Pandin MG. PLWHA's perspective on community stigma for getting social support and improving life quality in the digital era. medRxiv [Internet] 2022; 2022.01.17.22269334. Available from: <http://medrxiv.org/content/early/2022/01/19/2022.01.17.22269334.abstract>.
14. Koster Y, Taddele M, Aderaw Z, Tefera KT. Health-related quality of life and associated factors among HIV-positive individuals on antiretroviral therapy at Debre Markos Referral Hospital, Northwest Ethiopia. HIV AIDS Rev 2022; 21: 239-249.
15. Chaudhary S, Kakchapat S. Social stigma, discrimination, and their determinants among people living with HIV and AIDS in Sudurpashchim Province, Nepal. HIV AIDS Rev 2022; 21: 230-238.
16. Scofield D, Moseholm E. HIV-related stigma and health-related quality of life in women living with HIV in developed countries: a systematic review. AIDS Care 2022; 34: 7-15.
17. Pisheh SR, Eftekhari MB, Qorbani M, Mahmoodi Z. Relationships of social capital with health status and mental health in people

living with HIV: structural equation modeling. *HIV AIDS Rev* 2022; 21: 208-214.

- 18. Wiginton JM, Murray S, Kall M, Maksut JL, Augustinavicius J, Delpech V, et al. HIV-related stigma and discrimination in health care and health-related quality of life among people living with HIV in England and Wales: a latent class analysis. *Stigma Health* 2023; 8: 487-496.
- 19. Van Der Kooij YL, Kupková A, Den Daas C, Van Den Berk GEL, Kleene MJT, Jansen HSE, et al. Role of self-stigma in pathways from HIV-related stigma to quality of life among people living with HIV. *AIDS Patient Care STDS* 2021; 35: 231-238.
- 20. Turan B, Budhwani H, Fazeli PL, Browning WR, Raper JL, Mungavero MJ, et al. How does stigma affect people living with HIV? The mediating roles of internalized and anticipated HIV stigma in the effects of perceived community stigma on health and psychosocial outcomes. *AIDS Behav* 2017; 21: 283-291.
- 21. Nursalam N, Efendi F, Tristiana D, Misutarno M, Priyantini D. Family empowerment model based on belief and health related quality of life among housewives with HIV/AIDS. *Syst Rev Pharm* 2020; 11: 246-251.
- 22. Andersson GZ, Reinius M, Eriksson LE, Svedhem V, Esfahani FM, Deuba K, et al. Stigma reduction interventions in people living with HIV to improve health-related quality of life. *Lancet HIV* 2020; 7: e129-e140. DOI: 10.1016/S2352-3018(19)30343-1.
- 23. Reinius M, Wiklander M, Wettergren L, Svedhem V, Eriksson LE. The relationship between stigma and health-related quality of life in people living with HIV who have full access to antiretroviral treatment: an assessment of Earnshaw and Chaudoir's HIV stigma framework using empirical data. *AIDS Behav* 2018; 22: 3795-3806.
- 24. Winangun IMA, Sukmawati DD, Gayatri AAAY, Utama IMS, Somaia KA, Merati KTP. Hubungan stigma dan lama terapi HIV/AIDS terhadap kualitas hidup pasien HIV/AIDS di Poliklinik VCT RSUP Sanglah Denpasar. *J Penyakit Dalam Udayana* 2020; 4: 9-13.
- 25. Rydström LL, Wiklander M, Navér L, Ygge BM, Eriksson LE. HIV-related stigma and health-related quality of life among children living with HIV in Sweden. *AIDS Care* 2016; 28: 665-671.
- 26. Gottert A, Friedland B, Geibel S, Nyblade L, Baral SD, Kentutsi S, et al. The people living with HIV (PLHIV) resilience scale: development and validation in three countries in the context of the PLHIV Stigma Index. *AIDS Behav* 2019; 23 (Suppl 2): 172-182.
- 27. Ter Haar AM, Van den Hof M, Scherpbier HJ, Oostrom KJ, Haverman L, Pajkrt D. Health-related quality of life of perinatally HIV-infected young people: a longitudinal study. *AIDS Care* 2022; 34: 263-271.