# Coping with HIV Stigma among People Living with HIV in Yogyakarta, Indonesia: A Mixed-Methods Approach

Indonesian Nursing Journal of Education and Clinic (INJEC)
10-17
Volume 6, Issue 1, June 2021
DOI: 10.24990/injec.v6i1.311
injec.aipni-ainec.org/index.php/INJEC/index
Received : 2020-07-31
Accepted : 2020-09-25
The Association of Indonesian Nurse Education Center (AINEC)

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## Abstract

**Introduction:** People living with HIV are related to experience stigma and discrimination. Stigma can disrupt mental health and PLHIV have coping strategies to overcome internalize stigma. This study aimed to describe how PLHIV cope with HIV stigma.

**Methods:** This study used explanatory design. The quantitative data were collected to describe the internalized HIV stigma with 100 participants using a questionnaire and analyzed using multiple regressions. The qualitative data from the second phase were used to build on or explain the qualitative data with 14 participants using purposive sampling method and analyzed using thematic analysis.

**Results**: The participants reported to have low extent of internalized HIV stigma (mean=1.80) and the highest item was feeling guilty (mean=2.2) using quantitative analysis. The demographic profile were not significant predictors of internalized HIV stigma. The result from qualitative analysis was the coping internalized HIV stigma among PLHIV divided by negative and positive coping stigma, such as emotional and cognitive coping, behavior coping, social coping.

**Conclusion:** PLHIV have low extent of internalized stigma. The coping internalized HIV stigma among PLHIV was divided by negative and positive coping stigma.

## Keywords

coping; HIV/AIDS; Indonesia; mental health; stigma

## INTRODUCTION

Human immunodeficiency virus (HIV) can infect any person. A person who is infected with HIV can have Acquired Immunodeficiency Syndrome (AIDS) in several years. They can use antiretroviral drugs to slow down the process of the viruses. If left untreated, HIV reduces the number of CD4 cells (T cells) in the body and can damage immune system that fights infection (HIV.Gov, 2017). There are untreated cases because they do not want to be examined and feel ashamed of their HIV status.

There are 7.8 million HIV-related deaths and 30 million new HIV infections have been averted since (WHO, 2020). There are as many as 143.078 people with HIV, and AIDS sufferers as much as 54.018 people in Indonesia. Until September 2015, there are 3146 wherein 2078 are men, 1000 women and 68 unidentified in Yogyakarta. The amount increases every year. There are a lot of reasons

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why people get exposed to HIV. Anyone who is unprotected from sex with an infected partner could be affected by HIV regardless of sexual orientation, man or woman, young or old, white-or-black skinned. A group riskily exposed to HIV is Lesbian Gay Bisexual Transgender (LGBT), sex worker, and injection drug users.

People living with HIV (PLHIV), families of PLHIV, and people with high risk of HIV infection are related to experience stigma and discrimination. HIV-related stigma refers to the beliefs, feelings and attitudes and discrimination refers to the action (CDC, 2019).

PLHIV have negative consequences of stigma such as loss of jobs and violence and threats to their personal well-being because of their status. Research suggests that stigma can be either felt or enacted, feelings of blaming and distancing the concept of felt stigma can be included. Enacted including discrimination with PLHIV and felt stigma is the internalized stigma by PLHIV (Lekas, Siegel and Leider, 2011).

Stigma can disrupt mental health because it is deeply hurtful and may impede getting a treatment and recovery. Stigma can influence mental health because people who felt stigmatized increase the risk of depressions and mental illness (Shrivastava, Johnston and Bureau, 2012). Self-stigma can make people with HIV afraid to seek treatment and to disclose the identity for fear of rejection by family or society (Puspitasari and Kustanti, 2019).

Everyone is coping to face the problem, including PLHIV. They have coping strategies to overcome internalize stigma. The coping of every individual will be different. There are people who can solve the stressor problem well, while there also who cope poorly. The worst effect of poor coping is that they can commit suicide (Zhang *et al.*, 2014).

Based on the researcher's experience, on 2014, there were many health workers who did not treat PLHIV very well and afraid that they might get infected with HIV from the

Table 1. Distributions of the Participants According to Demographic Profiles

| Demographic Profiles | | Frequency | Percentage |
|---|---|---|---|
| **Age** | 15-19 | 2 | 2% |
| | 20-24 | 12 | 12% |
| | 25-29 | 25 | 25% |
| | 30-34 | 21 | 21% |
| | 35-39 | 15 | 15% |
| | 40-44 | 15 | 15% |
| | 45-49 | 6 | 6% |
| | 50-54 | 2 | 2% |
| | 55-59 | 2 | 2% |
| | **Total** | 100 | 100% |
| **Gender** | Male | 58 | 58% |
| | Female | 42 | 42% |
| | **Total** | 100 | 100% |
| **Education** | Elementary School | 14 | 14% |
| | Junior High School | 15 | 15% |
| | Senior High School | 54 | 54% |
| | Undergraduate | 17 | 17% |
| | **Total** | **100** | **100%** |
| **Occupation** | Government Sector | 1 | 1% |
| | Private | 65 | 65% |
| | Student | 11 | 11% |
| | None | 23 | 23% |
| | **Total** | **100** | **100%** |
| **Civil status** | Single | 53 | 53% |
| | Marriage | 23 | 23% |
| | Widow | 24 | 24% |
| | **Total** | **100** | **100%** |
| **Year of diagnosis** | 1-3 years | 59 | 59% |
| | 4-6 years | 26 | 26% |
| | 7-9 years | 6 | 6% |
| | 10-12 years | 6 | 6% |
| | 13-15 years | 3 | 3% |
| | **Total** | **100** | **100%** |

Table 2. The Extent of Internalized HIV Stigma Among the Respondents

| Indicators | Mean | SD | Verbal Interpretation | Rank |
|---|---|---|---|---|
| I think other people are uncomfortable with me. | 1.71 | 0.64 | Very low extent | 9 |
| I feel people avoid me because of my illness. | 1.61 | 0.85 | Very low extent | 10 |
| I fear I will lose my friends if they learn about my illness. | 2.18 | 1.003 | Low extent | 2 |
| I avoid getting treatment | 1.36 | 0.65 | Very low extent | 12 |
| I feel I wouldn't get good health care if people know about my illness. | 1.5 | 0.62 | Very low extent | 11 |
| I fear my family will reject me if they learn about my illness. | 1.83 | 0.997 | Low extent | 5 |
| I blame myself. | 1.99 | 0.91 | Low extent | 4 |
| I feel others blame me. | 1.8 | 0.87 | Low extent | 6 |
| I feel ashamed. | 2.02 | 0.920 | Low extent | 3 |
| I feel guilty. | 2.2 | 1.024 | Low extent | 1 |
| I have low self-esteem. | 1.74 | 0.83 | Very low extent | 8 |
| I feel I should be punished. | 1.76 | 0.88 | Low extent | 7 |
| Mean | **1.80** | | **Low Extent** | |
| **Median** | **2** | | **Low Extent** | |

Table 3. Demographic Profile Significantly Predict Internalized HIV Stigma

| Regression | Coefficient Regression | P | Decision | Interpretation |
|---|---|---|---|---|
| **(Constant)** | 433.098 | .351 | | |
| **Age** | -.125 | .171 | Accept null hypothesis | No significant predictive relationship |
| **Gender** | .016 | .993 | Accept null hypothesis | No significant predictive relationship |
| **Education** | -.414 | .599 | Accept null hypothesis | No significant predictive relationship |
| **Occupation** | -1.317 | .107 | Accept null hypothesis | No significant predictive relationship |
| **Civil status** | 1.964 | .082 | Accept null hypothesis | No significant predictive relationship |
| **Year of diagnosis** | -.202 | .380 | Accept null hypothesis | No significant predictive relationship |

Table 4. Themes

| | Negative Coping | Positive Coping |
|---|---|---|
| **Emotional Cognitive** | Self-Blame | Acceptance |
| | Fear | Introspection |
| | Shame | Self-Encouragement |
| | Suicidal Ideation | Hope |
| **Behavior** | Substance Abuse | Changing Life Pattern |
| | Suicide Attempt | Engaging Diversion Activities |
| | | Involvement In HIV Programs |
| **Social** | Silence | Accessing Support From Other PLHIVs |
| | Self-Isolation | Straitening Spiritual Connection With God |

patients. The previous research of the researcher about "Qualitative Study of HIV/AIDS Prevention Behavior (Knowledge, Attitude and Practice) by Female Sex Workers in Bantul" found that the respondents felt afraid to find treatment or just control their condition because of the stigma (Puspitasari and Kustanti, 2019). Therefore, the researcher conducted this study about coping with stigma among of PLHIV in Yogyakarta, Indonesia.

## MATERIALS AND METHODS

This research study used a mixed method approach explanatory design which is sequential design with qualitative data collected in the first phase, followed by qualitative data collection in the second phase. The variety of explanatory design is the participant selection model, in which the first stage of quantitative data is in the service of the second phase qualitative component. In this model, information about the characteristic of a large group, as identified in the first phase, is used to purposefully select participants in the second dominant phase (Polit and Beck, 2012). The quantitative descriptive correlational to describe the relationship among demographic profile and internalized HIV stigma. Qualitative design used descriptive qualitative describe and

explain the coping internalized HIV stigma among PLHIV.

Participants of this study are people living with HIV in an HIV community in Yogyakarta. The study included 100 purposively sampled participants for its quantitative component. The criteria for quantitative sampling are either male or female, 18 years old and above, accessing the health care facility, self-reported HIV+, willing to participate in the study. The G power score is 80% with minimal sample is 65 participants. The sampling method for qualitative is purposive sampling with 14 participants.

The questionnaire was composed of 12 items about internalized stigma. Four items were about distancing, and eight items were about blaming. The questionnaires used a 4-point Likert-type scale ranging from 1 to 4 and were designed to determine how often individuals have thoughts and feelings of being stigmatized or put in jeopardy because of their illness. The response choices were 1 = not at all, 2 = sometimes, 3 = often and 4 = always. The questionnaire has validated by expert's professor in nursing area and language. The researcher used Pearson Product Moment with level of significant at 0.05 for a two tailed test. The number of participants was 20 and R table was 0.444. For reliability, the researcher used Cronbach's Alpha for the 12 valid items. The result was reliable with Cronbach's Alpha score 0.922.

The internalized HIV stigma score and the median were computed. The half above the median was categorized as higher internalized HIV stigma group and lower the median as lower internalized HIV stigma group. The researchers ranked the participants based on their score for interview. The interview was selected from both the highest and lowest, converging to the median until data saturation was achieved. The criteria for qualitative sampling were the respondents who have a high level of internalized stigma and the respondents who have a low level of internalized stigma. The participants for qualitative analysis were 14 participants with seven participants with low level of internalized HIV stigma and seven participants with high level of internalized HIV stigma. The exclusion criteria were minors and PLHIV with debilitating physical conditions.

Qualitative was conducted after the researcher gets the result from quantitative analysis. This study used in depth interview with semi-structured interview and open-ended questions with. The questions were: Can you share with me any of your HIV stigma experience? How did you feel when you experience HIV stigma? How did your HIV stigma affect your life? What do you do to cope with HIV stigma? The qualitative data were analyzed using thematic analysis. The researcher was given an ethical clearance in the Philippines and Indonesia afterwards.

## RESULTS

Based on these results of the participants' data, it can be concluded that the majority belongs to age bracket range 25-29 with the frequency of 25 participants (25%). According to the gender, there are more males with a frequency of 58 (58%) male participants. According to the education level, the majority of the participants is senior high school with a frequency of 54 (54%). The majority occupation of the participants is in the private sector with a frequency of 65 (65%). The civil status of the participants is dominated by a single with a frequency of 53 (53%), and as to the year of diagnosis of the participants, the most amount is the bracket range 1-3 years with a frequency of 59 (59%).

There were 12 questionnaires with seven questionnaires with low extent and five questionnaires with very low extent. The average of the extent of internalized HIV stigma is 1.80 or low extent, it can be seen in Table 2.

Table 3 shows the demographic profile significantly predicted internalized HIV stigma among the 100 participants analyzed with multiple regressions. Based on the table, it clearly shows that the P value of the demographic profile is greater than .05 indicating the acceptance of the null hypothesis. This result indicates that the null hypothesis is accepted for all aspects in demographic profile, so there is no significant relationship between demographic profile and internalized stigma.

There are two coping stigmas, such as negative coping stigma and positive coping stigma. The copings have three themes; emotional and cognitive, behavioral and social. The negative emotional and cognitive coping

have four sub-themes; self-blame, fear, shame and suicidal ideation. It can be seen in Table 4.

## DISCUSSIONS

The data from table 2 show the mean of internalized HIV stigma about blaming is 1.86 which means low extent. The highest indicator score is about guilt with a low extent (mean score = 2.2), meaning most of the participants in this study feel guilty with their status of HIV positive. Ashamed, guilty and self-blame are the factors for internalized HIV stigma among PLHIV (Hasan *et al.*, 2012). The lowest indicator score is *avoiding getting treatment* with very low extent (mean score = 1.36). Participants of this study less to avoid get treatment mean most of them aware to get the treatment in the hospital or health services. Different with Gohain and Halliday (2014) research, they found that the level of internalized stigma among PLHIV was moderate, with just a small proportion who reported a high level of internalized stigma. They also found that females with high internalized HIV stigma also have a high depression level and anxiety. This study found that the level of internalized HIV stigma among PLHIV in Yogyakarta is low extent. This finding was proven in Hasan's research ( 2012) found that the majority of PLHIVs felt low internalized stigma.

The data analysis from table 3 there was no significant predictor of internalized HIV stigma of age, gender, education, occupation, civil status, year of diagnosis. Emlet *et al.*, (2015) in their research found the internalized HIV stigma was significantly lower for older adults compare to the younger age group. The interaction differs because there was no age effect among individuals who were not depressed. The depression is not researched in this study.

The genders, either male or female, will not affect internalized stigma. Webel (2014) said man with HIV may experience less stress than women. Women were reported to have higher internalized stigma level than men, whereas no significant relationship to gender differences in perceived stigma (Li, Lin and Ji, 2017). Level of education does not affect the internalized stigma because of the lack of HIV education in the school. The internalized stigma is not significantly different across educational levels; HIV stigma is shaped by the sociocultural (Li, Lin and Ji, 2017).The PLHIVs are stigma themselves may be perhaps of the sociocultural aspect in the community that HIV positive related to the moral.

The amount of PLHIV who stopped working or did not apply for a job is high among non-poor group than the poor group (Hasan *et al.*, 2012). Hasan's research also found that there was no significant relationship between occupation and internalized stigma and was no significant relationship between internalized HIV stigma and marriage status. Gohain and Halliday (2014) found that socio-demographic has not been found to be significant with internalized stigma, but social relationship stigma has been found to differ according to the current health status of PLHIV. The research conducted by Pantelic *et al.*, (2017) found internalized stigma associated with anticipated stigma, depressive symptoms and urban household location, but not associated with demographic profile.

The thematic analysis from table 4 showed the themes such as negative coping stigma and positive coping stigma. The copings have three themes; emotional and cognitive, behavioral and social. Negative coping is when people try to deal with the stressful situation in ways that cause more harm than good (U.S. Department of Veterans Affairs, 2020). There are 3 types of negative coping that emerged from the data; (1) Negative Emotional and Cognitive Coping, (2) Negative Behavioral Coping, (3) Negative Social Coping.

Emotion through cognition is inextricably associated with human life. Cognitive progress helps to manage emotion or feeling and control the emotion (Garnefski, Kraaij and Spinhoven, 2001). The participant's cognitive to manage their feeling about internalized stigma and control the effect of their emotion about internalized HIV stigma. The self-blame among PLHIVs has a higher internalized stigma score because of what they have experienced. PLHIV blamed themselves and others like their husband because they got HIV from others or they got it because of their risk behavior. This was proving that PLHIV with a level high and low level of internalized stigma blame themselves. Self-blame is associated with low expectation (Sheridan *et al.*, 2011) and significantly associated with higher level of stigma (Mo and Ng, 2017). PLHIV concern

about fear was that they can be a risk to the partner or family and the virus will be causing their death. Fear also contributes to high level of stigma in China, the fear about the future (Mo and Ng, 2017).

The behaviors that harmful and bad, the negative coping to quick fix avoid painful emotion (WYG, 2017). HIV can affect anyone, but the risk of infection is significantly higher in people suffering from substance abuse. It can promote the risk of early infection and some substances that are abused may also affect disease progression and impair the effectiveness of treatment (Hardey *et al.*, 2019). HIV can affect anyone, but the risk of infection is significantly higher in people suffering from substance abuse. It can promote the risk of early infection and some substances that are abused may also affect disease progression and impair the effectiveness of treatment (Hardey *et al.*, 2019).

Negative social coping can be a factor contributing to impact the quality of life (Rapp, Cottrell and Leary, 2001). From the findings' PLHIVs with high level of internalized HIV stigma did not disclose their status because they are ashamed and afraid with the people's response. The most common reason for non-disclosure was the fear of abandonment (Ssali *et al.*, 2010). PLHIVs manage disclosure to avoid damage to themselves and the relationship (Slavin *et al.*, 2011). The participants also isolated themselves, perhaps because they feel they will be avoided by others. The illness can cause social isolation; they feel shunned by others in social situation (Lavoie, 2015).

Positive coping means coping with problems in a positive way, such as problem solving to fix the problems, fix the problem based on the cause, think about good and bad, find the way to fix the problem in spiritual way or emotion (Changing Minds, 2017). By engaging in positive coping, PLWHs may experience less stress in response to the stigma (Earnshaw *et al.*, 2014). There are 3 types of positive coping that emerged from the data, (1) Positive Emotional and Cognitive Coping, (2) Positive Behavioral Coping, (3) Positive Social Coping.

PLHIV with low level of internalized HIV was better accepted themselves than participants with high levels of internalized HIV stigma. Acceptance can directly address social isolation (France *et al.*, 2015), who is proven that there are three participants with high level of internalize HIV stigma who experienced self-isolation compared to participants with low level of internalized HIV stigma. The participants with low level of internalized HIV stigma said that she hopes to have a partner that she can live for 50 years more and the hope also came from family support. The support from the family can give hope to the participant.

Coping behavior is an action during or after a stressful situation (Henson *et al.*, 2012). Eating healthy food can make someone live longer combined with exercise (Glover, 2016). The participant seeks to the health worker to help him manage the stress situation. PLHIV with low level of internalized HIV stigma used another support system like the health worker. Doing some hobbies can give so much fun in life and help to reduce stress with engaging something we like (Skilled At Life, 2017).

Coping strategies may relate between social support and emotional well-being (Kim *et al.*, 2010). PLHIVs with high level of internalized HIV stigma accessed PLHIVs support by finding a companion referred by the hospital and got health coverage. They also strengthen their spiritual connection with God by thanking Him because what He does in their life and pray. PLHVs find a religious way as a self-care practice; they use spirituality as a coping strategy for chronic health conditions (Musheke, Bond and Merten, 2013).

Based on the results of the study, a mental health promotion program has been created which will be conducted with 20 PLHIVs, 2 speakers (health worker and psychiatrist) and eight commissions to manage the program. The time duration for the program will be a series of programs to really support the participants. Topic for the program is HIV/AIDS, emotional and cognitive coping stigma, behavior coping stigma and social coping stigma with methods brainstorming, lecture and discussion.

## CONCLUSION

Most of the PLHIV in Yogyakarta are male 25-29 years old, senior high school graduate, work in private sector, single and was diagnosis 1-3 years. They have low extent of internalized stigma and demographic profile was not

significant predictors of internalized. The coping internalized HIV stigma among PLHIV was divided by negative and positive coping stigma, such as emotional and cognitive coping stigma, behavior coping stigma, social coping stigma. A program is created to help PLHIV to overcome the internalized HIV stigma with series program.

### *Acknowledgement*

Thanks to all authors and respondents for participating in the study.

### *Conflict of Interest*

None.

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