







Exploring the Experience of Stigma among People Living with HIV in Bali, Indonesia: A Qualitative Phenomenological Study

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Abstract

Background: Human immunodeficiency virus (HIV)-related stigma continues to be a serious problem for people living with HIV (PLWH). This study aimed to explore stigma experience among PLWH in Bali, Indonesia.

Methods: This research was a qualitative descriptive phenomenological study. With the help of a local clinician-researcher and the staff of the United Nations Program on AIDS Commission, Bali, 10 participants were recruited by purposive sampling and participated in semi-structured interviews via WhatsApp online audio from April to December 2021. Data were analyzed using Colaizzi's process.

Results: The following three themes emerged: (1) experiencing discrimination, (2) getting stronger through stigma experiences, and (3) receiving support. Interviews revealed that PLWH in Bali experience stigma and discrimination across settings, including communities, families, friends, employers, and health care. Some participants could turn the pressure of stigma into a source of strength, making them psychologically and mentally strong. This phenomenon mostly happened when the patients had positive attitudes toward illness and good coping mechanisms.

Conclusions: This study showed the importance of support from family, friends, and organizations in surviving stigma. For PLWH, having a sense of self-support and resilience and adaptive mechanisms also help ease the negative effects of stigma and discrimination.

Keywords: AIDS, discrimination, HIV, qualitative research, social support, social stigma

INTRODUCTION

Human immunodeficiency virus (HIV)-related stigma continues to be a serious social problem for people living with HIV (PLWH) in Indonesia.¹ Around 38 million people in the world are currently living with HIV, and 640,000 of them are in Indonesia.² According to statistical data published in 2016, the majority of patients with HIV in Indonesia consist of injecting drug users (28.8%), men who have sex with men (25.8%), and transgender people (24.8%).³ National statistics data showed that the majority of PLWH in Indonesia are concentrated in the provinces of Papua, Jakarta, West Java, East Java, North Sumatera, and Bali.²

The HIV pandemic has been on the world stage disease for 40 years.⁴ Many studies have been conducted not only on medication and treatment for this disease but also on other aspects such as social, political, and economic.^{5,6}

Thus, expanding the theoretical knowledge about HIV stigma, harassment, violent attacks on PLWH, family rejection, financial problems, or refusal of medical treatment is important in fully understanding this disease.⁷⁻¹¹ Despite the numerous actions taken by the Ministry of Health in Indonesia to provide medication, treatment, and care to PLWH and to prevent complications among this population, HIV remains a widespread disease and its stigma remains a potent barrier to treatment for many HIV positive individuals worldwide, including in Indonesia.¹

According to Goffman, stigma is defined as "an attribute that reduces a person in the minds of others from a whole and usual person to a tainted or discounted one."¹² When applied to patients with HIV, stigma refers to irritational or negative attitudes, behavior, and judgment toward PLWH or those at risk of acquiring HIV.¹⁰ Stigma among PLWH has existed since the beginning of the HIV pandemic, when many of these patients experienced devastating rejection and humiliation from the society directed at the Lesbian, Gay, Bisexual, Transgender and Queer community who have long been associated with HIV.^{8,11} Stigma can be extremely harmful to people with HIV because it creates numerous problems that could

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negatively affect their health and make their life circumstances difficult or unbearable.¹³

Stigma and discrimination against PLWH often occur in families, which may include parents, brothers and sisters, extended family, and in-laws.^{1,14,15} Discriminatory treatment and actions include refusing to share food and rooms with PLWH, separating their personal items, such as eating utensils, from a family member with HIV, and ostracizing PLWH by not including them in shared activities such as cooking food or family gatherings.^{1,14-16} Neighbors, friends, and co-workers may also stigmatize and discriminate against PLWH manifested as rejection, being ignored, shunning, verbal abuse, and harassment.¹⁷ In the workplace, stigma and similar discrimination against PLWH may involve social isolation, indifference, or being fired from their jobs. In healthcare settings, stigma and discrimination take many forms, including criticizing, blaming, yelling at PLWH, throwing medical records in their faces, ignoring them or refusing to provide treatment and care, and unnecessarily referring patients to other health facilities. Although many studies have described how patients with HIV are being stigmatized and discriminated, limited attention has been paid to their experience of living with HIV-related stigma and its impact on people's daily lives, especially in the Indonesian context.

Several researchers in Indonesia showed that many PLWH continue to suffer from negative attitudes toward them.¹⁸ These people experience stigma and discrimination in different settings, including family and communities, health care facilities, and workplace.¹ Being stigmatized by family and community can drive people to engage in risky sexual behavior and increase their sense of shame about their illness.¹⁹ Stigmatization from health care providers may interfere with medication adherence by discouraging PLWH from seeking health care, thus increasing morbidity and mortality rates.^{20,21} In addition, discrimination and unpleasant behavior from employers, such as employment rejection and harassment, can cause financial harm and increase unemployment and poverty among PLWH.^{11,19,21}

HIV stigma and discrimination have been associated with poor outcomes in terms of mental well-being, physical health, and social life in the HIV positive population. These people are prone to depression, stress, and anxiety, and experiencing a poor quality of life. In terms of medical outcomes, stigma and discrimination affect access and adherence to antiretroviral therapy, prevention programs, and treatment and may also result in impaired social interaction with family, friends, colleagues, and neighbors. This study will contribute significantly to the current level of knowledge on this topic in Indonesia and provide information for health care practitioners or policy makers in government and

non-government organizations who are trying to eliminate the social impact of stigma and discrimination among PLWH and improve health outcomes in Indonesia and the world.

Although 35 years have passed since the first reported of HIV widespread outbreak in Indonesia in 1987, patients positive for HIV in this country continue to suffer from stigma and discrimination similar to those in other parts of the world. Only a few studies, particularly in the past 5 years, have explored stigma experience among PLWH in Indonesia. Therefore, this study aimed to reveal the voices of PLWH in Indonesia and their stigma experiences.

METHODS

Ethics approval and consent to participate

The study protocol was reviewed and approved by an independent ethics committee. All participants gave informed consent. Interviews and data collection were anonymous. The transcriptions and recordings were secured and coded in a protected file. Refusal to participate in the study entailed no penalties whatsoever.

Conceptual framework

This study followed the HIV stigma framework developed by Earnshaw and Chaudoir,²² which holds that stigma is an unappreciated attribute of HIV/AIDS and has a detrimental effect on PLWH through various mechanisms.^{15,23} This framework asserts that discrimination or unfair treatment is one of the mechanisms by which people with HIV experience stigma.^{15,23} It also includes a process for influencing social norms, values, and institutional policies related to negative attitudes and behaviors toward PLWH. These discriminatory attitudes have a negative impact on psychological, social, and health outcomes that affect the lives of PLWH and limit their opportunities (e.g., access to health care) and well-being.^{15,23}

Design and participants

In this qualitative descriptive phenomenological study, in-depth and semi-structured interviews were conducted via WhatsApp from April to December 2021.^{24,25} Purposive sampling was used to recruit 10 participants referred by a local clinician-researcher and the staff of the United Nations Program on AIDS (UNAIDS) Commission, Bali. The sample size was determined using the saturation principle in qualitative research, which holds that data collection should stop at the point when new information on the research topic is no longer forthcoming.¹⁴ Inclusion criteria were as follows: at least 18 years old, diagnosed with HIV for at least 6 months, and a stigma score of 12 or higher (ranging from 12 to 48). Exclusion criteria were as follows: foreign residence, refusing to participate, and

having other stigmatized diseases, such as tuberculosis, certain skin diseases, and psychological disorders.

Data collection

Owing to the researcher's lack of familiarity with patients, the staff from the UNAIDS commission in Bali and a local clinician–researcher helped introduce the author to the patients with HIV and explained the goals and purpose of the study. One day before the interview, the HIV Stigma Scale was administered to the participants to measure their stigma experience and ensure their qualification. This 12-item short version scale was developed by Reinius, Wetterged, and Wiklander in 2017 and had a Cronbach's alpha >0.7 and scores ranged from 12 to 48, with a high score indicating a high level of stigma.²⁶ Instruments were back-translated from English to Bahasa version and processed for content validity. The scale was translated to Indonesian, transformed into an online form, and sent to participants before the interview. The participants gave consent prior to the interviews.

On the interview day, the participants were given a brief demographic questionnaire and underwent a semi-structured interview. Some of the questions asked to the participants during the interview were as follows: (1) How long have you been experiencing stigma related to your HIV status? (2) What are your feelings about being stigmatized? (3) What do you usually do when you experience stigma/when someone stigmatizes you? (4) What do you find difficult about dealing with stigma? (5) Do you believe that someone should help you when you experience stigma or discrimination? and (6) Is there anything else you would like to tell me regarding your experience of stigma related to your HIV status? Most interviews lasted for 45–60 minutes and were transcribed verbatim. Notes and audio recordings of interviews were taken with permission by the investigator. Transcript review for accuracy and saturation and result discussion were performed by the project supervisor (second author).

Data analysis

Colaizzi's phenomenological method was used to quantitatively analyze our data on the participants' stigma experience from the interviews.^{24,27} According to this technique, the data were analyzed in seven consecutive steps: the researcher must (1) collect participant statements and descriptions and transcribe them verbatim; (2) understand deeply the meaning of all statements that have important meaning, (3) extract important phrases, (4) conceptualize important themes, (5) classify concepts and themes, (6) construct comprehensive theme descriptions, and (7) verify data according to the four criteria set by Lincoln and Guba.²¹ First, the interviews were transcribed verbatim by the principal investigator. The results were then read several times by the researcher and project supervisor to find

significant and meaningful phrases and group them into themes. After that, the findings were then incorporated into a comprehensive, in-depth account of the phenomena. Following the collection of descriptions and themes, some participants were approached for a second time by telephone interview to confirm the findings. Additional information obtained was then incorporated into the final description. Similar to the study by Guba and Lincoln,²⁸ the following four criteria were used to ensure the accuracy of the data: credibility, dependency, conformability, and transferability. Themes and subthemes were discussed by the principle investigator and project supervisor, during which their opinions conflicted until they came to an agreement.

RESULTS

Demographic characteristics

All the participants were females (100%) with a mean age of 43.5 years. Most of them graduated from high school (60%), had jobs (40%), and were widowed (40%). Among the participants, 80% had been diagnosed with HIV for at least 4 years, and the average stigma score was 25.7 (Table 1).

Themes

Analysis of interview transcripts revealed the following three main themes: experiencing discrimination, getting stronger through stigma experiences, and receiving support.

TABLE 1. Demographic characteristics of the participants (N = 10)

Characteristics	n (%)
Age (Mean, SD)	43.5 (2.12)
Gender	
Male	0 (0)
Female	10 (100)
Education level	
Primary	0
High school	6 (60)
College/University	4 (40)
Graduate school	0
Marital status	
Single	2 (20)
Married	2 (20)
Widowed	4 (40)
Separated	2 (20)
Employment status	
Employed	6 (60)
Unemployed	4 (40)
Time since HIV diagnosis	
+6 years	4 (40)
4-6 years	4 (40)
1-3 years	2 (10)
Less than a year	0 (0)
Mean HIV stigma score	25.7

Theme 1: Experiencing discrimination

Discrimination refers to the act of treating PLWH differently than those without HIV. In our study, some of the participants described themselves as being subjected to systematic disadvantage and discrimination in the workplace. Many had been denied employment because of their HIV status. One participant shared her experience in a job interview: *"Last time I had a job interview, they were very suspicious of me because I wrote on my CV that I had been volunteering at an HIV-advocacy organization. They asked me what kind of organization it was. They also asked about my health, because at that time I had just recovered from AIDS; my hair was just about to grow and my body was still thin. Maybe they noticed those symptoms as they looked at me carefully from head to toe. I may have looked like a person recently discharged from hospital."*(P1)

In global health care settings, the attitudes and manners of health care workers toward PLWH are a long-standing concern. According to the participants in this study, nurses and doctors sometimes do not treat them well; some were impolite, abrupt, and lacked empathy. One of the participants said: *"The first counselor was a doctor; he was so unfriendly and impolite to me. He also lacked empathy and was authoritarian. I still remember clearly his sentence, 'You have to follow my rules!, If you want to recover, if you want to be healthy, you need to follow my rules.' I then said, 'What kind of rules, doctor?' 'It doesn't matter, just follow my directions and do everything that I tell you to do.' I was absolutely shocked and scared because this doctor did not explain anything at all about my disease. As a new patient, I decided to leave the hospital immediately and refused further tests and medication."*(P2)

Other participants also described experiences of discrimination in health care settings, doctors refusing treatment, and other difficulties when attempting to access medical services. Another participant stated, *"There was (also) another incident when my youngest kid had herpes and I took him to the hospital for treatment. In the hospital, I told everything to the doctor about my kid: that he had small red bumps, pain, itchiness, and fever. I also told the doctor that my son was HIV positive and had no IRV therapy yet, based on his CD4 count. The doctor's response to hearing that my kid was HIV positive was shocking; he immediately refused to examine or to treat my child. This is clearly indicated that this doctor is stigmatized and discriminated against me and my son. I was very sad."*(P4)

Theme 2: Getting stronger through stigma experiences

In our study, many participants maintained positive thinking despite being stigmatized. According to them, stigma is essentially happening in their own minds and thoughts. One participant said, *"although stigma comes from society or from other people, in my opinion, stigma*

comes from ourselves. Stigma grows from inside our minds or our thoughts."(P1). Other participants similarly said that it is important for people with HIV to always think positively and change stigma into a source of strength. *"My family (my mother) also stigmatized me, however I choose to think positively. For example, when my mother is stigmatizing me, that means that my mother still lacks education and understanding."*(P3). Another participant said, *"To be honest, the more people stigmatize me, the stronger I get, so now I don't feel worried about talking to people about my HIV status."*(P8)

Theme 3: Receiving supported

In our study, many participants agreed that having strong and supportive relationships with family and friends is important and can be the first line of defense when facing societal discrimination or stigma. Mixed with reports of stigma experiences, positive experiences were also relayed by the participants. One of them explained the importance of support. She spoke of the support given by her family, how family support means so much to her, and how their relationships remained unaffected even after her family learned of her HIV status. *"I also show [people who stigmatize me] that my family always supports me. I hold it up as an example to other HIV positive patients to show that family support is possible."*(P1). Another participant also stated that *"When family supports us, we will not be so afraid if people know that we are HIV positive, because our family back us up."*(P7).

Other participants explained that receiving support from friends is also important for someone who is HIV positive. They stated that they need friends to lean on and trust more than anything. One participant said, *"My friends never judged me badly when they found out my HIV status. They were even very supportive and got closer. It seemed like they educated themselves about HIV on their own."*(P1)

Several participants were able to engage in social activity, charity, or organizations and found the experience really meaningful. They said that these activities could be a source of emotional support, knowledge about the disease, and a resource for seeking help. One participant stated that *"In 2011, I decided to join the association for HIV positive Indonesian women. Several years later, I was appointed chairman of this organization. Through this organization, I met with other HIV positive women from many backgrounds and received a lot of support from them."*(P2).

DISCUSSION

Many people diagnosed with HIV experience multiple layers of stigma that make their life difficult or unbearable.²⁹ In our study, many of the participants expressed concern about stigma coming from their own

family and friends, employers, and even health care workers. In the face of stigma related to HIV, knowledge and positive attitude toward the disease and good coping mechanisms are warranted turn this negative pressure into a source of strength.^{14,23} In this section, we discussed the experience of stigma and discrimination among PLWH in Bali, how they get stronger through stigma experiences, and their need for support particularly from family, friends, and social organizations that work with patients with HIV.

Almost all of the participants had experienced discrimination. One cause of stigma and discrimination is insufficient public knowledge about the disease, which leads to false perceptions about transmission and the risk of associating with a person who has HIV.^{15,23} Previous research in Indonesia showed that people avoid contact with those infected with HIV because of their fear of being infected.^{9,30} Owing to their lack of accurate knowledge, many people in Indonesia still believe that HIV infection is acquired through casual contact, for example, by shaking hands, eating together, and sharing a bathroom.^{1,18} Improving public health education, specifically teaching people about how HIV is transmitted, could help the public understand that this disease cannot be acquired through casual contact. Changing social attitudes may allow PLWH to easily seek care.

This study found that stigma and discrimination commonly occur in the working place. The participants reported that they have been denied employment because they are HIV positive. For example, one job recruiter interviewing a participant treated them differently by staring or looking at them fearfully from head to toe. Labor law in Indonesia prohibits employers from discriminating against PLWH in hiring and prohibits firing employees because of HIV infection.^{3,18,30} Furthermore, these laws specify that HIV testing is not required for prospective employees or job promotions and prohibit stigma and revealing the identity of employees with HIV.^{3,30} Promoting these laws in workplace settings and improving their enforcement are warranted. In addition, education about HIV transmission should be encouraged in the workplace so that the stigma and discrimination against PLWH can be reduced.

The interviews showed that stigma and discrimination in health care facilities are a common occurrence. It may include inappropriate behavior from health workers or refusal of treatment because health workers overestimate or overreact to the risk of virus transmission in their workplace. The occurrence of discrimination in health care facilities supported our conclusion that poor knowledge and lack of training among health workers are an underlying cause of stigmatizing behavior and poor treatment that PLWH

encounter in health care facilities. The curriculum for training doctors and nurses on how to handle patients with HIV is not standardized in Indonesia.³¹⁻³³ Although improved training about HIV in health care settings is still needed, progress has been achieved in the last 10 years.¹⁶ Published research and government reports showed a significant decline in stigma and discrimination in health care facilities in Indonesia because the staff has become knowledgeable and experienced in providing care to PLWH.¹⁸

Some of the participants mentioned that they experience stigma from their family members who believe that being HIV positive will bring shame onto the family and damage the family's relationship with extended family members and society. A couple of participants revealed that they were told to immediately leave home after disclosing their HIV status. Stigma and discrimination from family are particularly upsetting in Indonesia, where the culture traditionally supports strong bonds among family members. Society tells us that family is everything and is the primary place to look for support. Providing health counseling for the family members of PLWH can help them understand the risk of infection and how to care for and support their family member with HIV, such as by helping with adherence to treatment regimens. Such counseling could reduce stigma and discrimination and minimize the transmission of HIV within the family.^{34,35}

Some of the participants revealed that they could turn the pressure of stigma into a source of strength, making them psychologically and mentally resilient.^{5,11} This phenomenon mostly happened when the patients had positive attitudes toward living with their illness and good coping mechanisms, such as seeking support from a peer group, disclosing HIV status to a selected person, and strengthening relationships among family members.^{9,30} Some participants explained that thinking positively despite being stigmatized gives them a sense of power and self-support, which are crucial in surviving stigma. Improving their knowledge about the disease, teaching them about coping mechanisms for stigma, and educating them about resilience and self-support could help PLWH tackle the negative effects of stigma.^{35,36}

The participants reported the need for support from people around them to survive stigma. For PLWH, social support is a fundamental need for their psychological and physical well-being.³⁷ In the face of societal discrimination or stigma, a strong and supportive family or support from friends is a great advantage.¹ A couple of participants described how much family support means to them. Some are grateful that their close relationships remained unaffected even after they disclosed their HIV status. In addition, support from friends can make a huge difference: PLWH need friends they can rely on and trust so they do not feel alone,

isolated, and frightened. Moreover, engaging in social activity and charity or being involved in a network of people positive for HIV is an important source of resilience for PLWH.³⁷ These activities can provide a source of psychological support, information about the disease, and opportunities for seeking practical help.

Our study had several limitations. First, due to the small sample size and the use of purposive sampling, the findings might not be generalizable to other broad communities of PLWH in Bali or other provinces in Indonesia. Second, all of the participants are females; therefore, the results cannot be generalized to men and other genders. Third, other HIV positive populations, for example, men who have sex with men or transgender people, were not included. Hence, the information about stigma in this study does not provide a complete picture. Moreover, some of our interviews were brief because the participants had other activities. This circumstance may have limited the depth of information that was obtained from the interviews. In addition, only patients who were living with HIV were interviewed; valuable information from other people's perspectives, such as family members, friends, employers, and health care workers, was not obtained. Finally, age was not considered in the data analysis. The experience of stigma associated with HIV may differ between generations. Further research examining the impact of stigma and discrimination on PLWH is essential for developing a stigma reduction program in Indonesia.

In summary, the findings showed that many PLWH in Indonesia experience considerable disadvantages and systematic discrimination in various settings, including from families and friends, the community, or even from health workers. Similar findings have been reported in other countries. This study also provided interesting evidence that many PLWH in Indonesia expressed their ability to transform stigma into a source of strength and power. Having a constructive attitude toward the disease, knowledge, and adaptive mechanisms is one of the keys to successfully reducing the impact of stigma. This study also documented the need for support from families, friends, and community to help PLWH in Indonesia cope with social stigma and discrimination. The findings provide rich and detailed information that can be utilized to improve policies related to HIV and establish evidence-based interventions to fulfill the needs of PLWH and minimize the stigma and discrimination against them in Indonesia and other countries.

CONCLUSIONS

Even after 40 years of the HIV pandemic, the stigma and discrimination against PLWH remain common. Our findings showed that HIV-related stigma has a negative impact on PLWH and acts as a barrier to access healthcare services and treatment. Inadequate knowledge, misunderstandings

about transmission mode, and fear of infection can lead to stigma and discrimination against these patients. Therefore, providing training and education for communities and health care professionals is crucial to enhance their understanding of the disease and hopefully reduce the stigma. Medical professionals must be involved to ensure that public policy provides a supportive environment for PLWH and eliminates the HIV-related stigma.

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CONFLICT OF INTEREST

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