

Experience and management of stigma among persons living with HIV in Bali, Indonesia: A descriptive study

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Abstract

Aim: This study aimed to describe the level of HIV stigma experience and the HIV stigma management strategies used by persons living with HIV (PLWH) in Bali, Indonesia.

Methods: A cross-sectional descriptive study was conducted from March to May 2019. In total, 215 respondents were recruited using purposive sampling from hospitals and HIV private clinic. The research tools consisted of the demographic characteristics form, the 28-Item Internalized HIV Stigma Scale, and the Stigma Management Strategies Checklist. This study used descriptive statistics and non-parametric statistics to analyze the data.

Results: Overall, the transformed mean score of HIV stigma experience was at a low level (mean = 42.88, $SD \pm 17.59$). There was no statistically significant difference between demographic characteristics and HIV stigma ($p > .05$). Of the 38 stigma management strategies, prayer (70.7%) was reported as the most common, whereas forgiving one's spouse (4.1%) was the least utilized strategy of the respondents. The most often reported reason to manage stigma was to alleviate and/or avoid stress (68.8%). In addition, the most effective stigma management strategy was prayer (28.8%). Conversely, the least effective was staying alone (21.9%).

Conclusions: HIV stigma is present in Bali, Indonesia, and PLWH struggle to accept their HIV status. Furthermore, they use prayer as a stigma management strategy to get closer to God. The findings of this study could serve as evidence to inform HIV stigma reduction programs in the community. In addition, the development of faith-based stigma management interventions is recommended.

KEYWORDS

experience, HIV, Indonesia, management, stigma

1 | INTRODUCTION

HIV infection and its impacts are considered as one of the main global health concerns. The 2018 Joint United Nations Program on HIV/AIDS (UNAIDS) reported that the number of persons who were newly diagnosed with HIV infection globally in 2017 was 1.8 million; people

living with HIV (PLWH) were approximately 36.9 million, and the number of people who died during that year due to AIDS was around 940,000. Meanwhile, Indonesia is one of the countries where the HIV epidemic is rapidly increasing; it ranked second for AIDS-related deaths among Asia-Pacific countries in 2017 (UNAIDS, 2018).

HIV stigma has been commonly reported in many countries across the world, and it is known that it impacts on the lives of persons with HIV infection profoundly (Donnelly et al., 2016). In Canada, PLWH were found to describe their stigma experience as a feeling of “shame” and “guilt”. They tend to blame themselves as an infected person and fear to disclose their HIV status (Donnelly et al., 2016). Similarly, a study by Baugher et al. (2017) on HIV stigma in the United States found that 79.1% of PLWH experience negative feelings toward themselves. In India, heterosexual men with HIV infection report a high level of negative attributions toward themselves, whereas heterosexual women report experiencing a high level of stigma (Malavé, Ramakrishna, Heylen, Bharat, & Ekstrand, 2014). Moreover, HIV stigma leads to negative health outcomes such as an increased risk of opportunistic infections (Li, Morano, Khoshnood, Hsieh, & Sheng, 2018) and mental health disorders (Florom-Smith & De Santis, 2012). In China, HIV-positive men who have sex with men (MSM) were reported to have high rates of depression and use negative coping mechanisms (Li, Hsieh, Morano, & Sheng, 2016).

Due to its negative impacts, PLWH attempt to manage HIV stigma. Stigma management is a method to reduce or prevent the impact of HIV stigma (Sengupta, Banks, Jonas, Miles, & Smith, 2011). Rael et al. (2017) reported that PLWH use several strategies to manage it such as controlling the disclosure of their HIV status, educating others about HIV, viewing HIV as a manageable condition, and seeking support from family members and close friends. Furthermore, a qualitative study by Mhode and Nyamhanga (2016) revealed that spiritual devotion, accepting one's condition and illness, concealing being on antiretroviral therapy from other people, sharing experiences with other PLWH, and disclosing one's HIV status preemptively are used as ways by PLWH to manage the stigma they experience. Similarly, keeping one's HIV status a secret is a common strategy among PLWH in Nepal (Aryal, 2017).

In Indonesia, the majority of the population believes HIV is a punishment from God due to one's own bad or sinful behaviors, especially promiscuous sexual behaviors (Sulung & Asyura, 2019). However, studies on HIV stigma and its management as experienced by PLWH living in that country are scant. Previous research on HIV stigma has focused on prisoners living with HIV infection (Culbert et al., 2015). Indonesians tended to label HIV-infected prisoners as drug users or drug offenders. Furthermore, another study found that healthcare providers in Aceh, Indonesia had a high-level stigma toward PLWH (Harapan et al., 2015). Likewise, a high level of HIV stigma has been reported among nurses in Indonesia

(Waluyo, Culbert, Levy, & Norr, 2015). These negative attitudes lead PLWH to develop a sense of worthlessness and, consequently, a perception that they do not deserve to live (Aggarwal et al., 2018).

Both the HIV epidemic and the HIV stigma are pervasive in Bali. The first case of HIV in Indonesia was reported in 1987 in this province. According to the Denpasar AIDS Commission (2016), the risk for infection is the highest among the heterosexual population (77.7%), of the 20–29 age group (38%), and residing in the regency/city of Denpasar (39%). The total cumulative incidence in Bali has been reported at 15,839 people, and the mortality due to HIV/AIDS has been found to have an overall rate of 10% per year (Utami et al., 2017). Meanwhile, a qualitative study exploring HIV stigma and discrimination in Bali revealed that PLWH were stigmatized by healthcare providers (Merati, Supriyadi, & Yuliana, 2005), which compounded the negative effects of their disease and increased the barriers related to accessing HIV services. In addition, PLWH fear experiencing stigma when accessing antiretroviral therapy services, which are integrated in the public health centers of Bali (Januraga et al., 2018).

Due to the stigma attached to HIV infection, PLWH may have a limited contact with healthcare providers and prefer to use their own strategies to manage stigma on their own. However, a limited number of studies describing the strategies employed by PLWH to manage HIV stigma exists, and they have focused primarily on stigma reduction interventions that were navigated by healthcare providers (Suyanti, Keliat, & Daulima, 2018). Therefore, this descriptive study was aimed to describe the level of HIV stigma experience and the stigma management strategies among PLWH in Indonesia.

1.1 | Conceptual framework

The conceptual framework of this study was built upon the concept of HIV stigma by Sayles et al. (2008) and the Symptom Management Model (SMM) by Dodd et al. (2001). Sayles et al. (2008) conceptualized HIV stigma as a social process and characterized it as an experienced or perceived act of discrimination toward a person who is being stigmatized related to the treatment and/or other aspects of HIV infection including the socio-cultural aspect. They elaborate further that HIV stigma occurs when the person is subjected to stigma on account of his/her failure to conform to cultural norms, being identified as a member of a deviant group, and assuming a “spoiled identity” in the community. According to Sayles et al. (2008), HIV stigma consists of four domains—stereotypes, disclosure concerns, social relationships, and

self-acceptance. Stereotypes refer to the perception of the society, coworkers, and medical providers either feeling or thinking negatively about PLWH. Disclosure concerns reflect worries of PLWH regarding others knowing their HIV status, which includes concerns related to physical changes and responses received at the HIV clinic when meeting people. Social relationships involve the treatment by and reaction of people (outsiders) toward PLWH in social life and the effect of those reactions on personal relationships with family members, close friends, and healthcare providers. Self-acceptance connotes how comfortable the person infected with HIV is with his/her HIV diagnosis.

In addition, the SMM by Dodd et al. (2001) was adopted to guide the exploration of stigma management among PLWH. According to Dodd et al. (2001), symptom management is defined as the strategies an individual uses to prevent or manage a given symptom. In this study, HIV stigma is conceptualized as a social symptom where PLWH have internalized HIV stigma toward themselves.

2 | METHODS

2.1 | Study design, setting, and sample

A descriptive, cross-sectional design was employed. The respondents were purposively recruited from the outpatient department (OPD) in three hospitals and one HIV private clinic in Bali, Indonesia. Eligible participants were: (a) adults aged 18 years or above; (b) aware of their HIV-positive diagnosis; (c) cooperative and communicative; (d) able to read and understand Bahasa Indonesia; and (e) willing to participate in this study as indicated by the signed informed consent. The exclusion criteria in this study were (a) pregnancy and (b) age of 65 years or above. The Bartlett, Kotrlik, and Higgins formula for a descriptive study was used to determine the sample size. The calculated minimum sample size was 194 respondents. However, taking into consideration the non-response rate (10%), the total sample size of this study was established at 215. Data were collected from March to May 2019.

2.2 | Measures

2.2.1 | Demographic characteristics form for persons living with HIV (DCFPLWH)

This form was developed by the researchers based on a literature review related to stigma experience and

management. The DCFPLWH consists of 12 items—age, gender, sexual orientation, religion, race/ethnicity, level of education, employment status before and after HIV diagnosis, age at HIV diagnosis, duration of HIV diagnosis, place of residence, and persons with whom they lived.

2.2.2 | The 28-Item Internalized HIV Stigma Scale

The 28-Item Internalized HIV Stigma Scale was developed by Sayles et al. (2008). Permission to use the tool was obtained from the developers. The 28-Item Internalized HIV Stigma Scale consists of four subscales: stereotypes (12 items), disclosure concerns (5 items), social relationships (7 items), and self-acceptance (4 items). Each item is measured on a five-point Likert scale ranging from 0 (“none of the time”) to 4 (“all of the time”). The response scale values of two items are reversed for scoring before analysis. According to Sayles et al. (2008), the mean scores for the HIV stigma scale are transformed linearly to a range of 0–100, with a higher score indicating greater levels of HIV stigma, and the lower scores indicating lower levels of both perception and experience of HIV stigma.

The 28-Item Internalized HIV Stigma Scale was translated to its Indonesian version through a back-translation procedure (Polit & Beck, 2017). It also was tested for internal consistency using a Cronbach’s alpha coefficient for each subscale and as well as the overall scale. As it regards this study, the Cronbach’s alpha reliability of the Indonesian version is acceptable due to its high coefficient value ($\alpha = .92$).

2.2.3 | The Stigma Management Strategies Checklist (SMSC)

The SMSC was developed by the researchers. It was derived from our preliminary qualitative study. The questions were validated by three experts, and the scale content validity index (S-CVI) was 1.00. The SMSC consists of three parts, and the checklist form is the yes/no type. The first part comprises a list of 38 stigma management strategies used by PLWH. The second part asks about the reasons for managing HIV stigma. In the third part, the respondent was queried about the effectiveness of the stigma management strategies, and asked to rate them from the most effective to the least effective. The respondent was also asked what he/she does to manage HIV stigma and his/her reasons for doing so by asking to “check all that apply”, except for the part dealing with effectiveness, wherein the respondent was instructed to

choose one answer for the most effective and least effective strategy. A higher percentage was considered to indicate a larger number of stigma management strategies used by respondents to reduce stigma.

2.3 | Data collection procedure

This study was reviewed and approved by the ethics review board at the Center for Social and Behavioral Sciences Institutional Review Board, Prince of Songkla University (PSU IRB 2019–NSt 005) as well as the Research Ethics Committee of Faculty of Medicine, Udayana University/Sanglah Hospital (420/UN14.2.2.VII.14/LP/2019). In addition, permission was obtained from each hospital and the private clinic. After providing information about the purpose of the study, confidentiality or anonymity, and absence of harm to the respondents, a written informed consent was obtained from all respondents in this study.

After receiving approval from all the ethics bodies, the first author, NAJR, met the head nurse of the HIV OPD and a nurse at the selected settings to explain the purpose of the research as well as the inclusion/exclusion criteria. The role of the nurse was to approach the PLWH who met the inclusion criteria and inform potential respondents about the study and the data collection process. The nurse then gave a pre-informed consent form to the potential participants to sign. After that, the nurse accompanied the respondents to meet NAJR in a private room or the OPD's counseling room. Each respondent was given a brief explanation regarding the objectives and procedures of the study as well as its potential benefits. After agreeing to participate, he or she was asked to sign the informed consent. NAJR asked him or her to complete the questionnaires independently. All questionnaires were answered in approximately 15–25 min. After the respondents finished the questionnaires, NAJR checked for their completion.

2.4 | Data analysis

To analyze the data, descriptive statistics were used for demographic characteristics, HIV stigma experience, and HIV stigma management strategies. Demographic characteristics were analyzed using frequencies and percentages. The Mann–Whitney *U* test and the Kruskal–Wallis test were used to compare between each variable of demographic characteristics and HIV stigma experience. Furthermore, the HIV stigma experience was analyzed using range, mean, and *SD*. Non-parametric statistics, including the Mann–Whitney *U* test and the Kruskal–

Wallis test, were used to compare between demographic characteristics and HIV stigma experience, as the HIV stigma data set did not show a normal distribution. The SMSC data were analyzed using frequencies and percentages for each part of the stigma management strategies.

3 | RESULTS

3.1 | Demographic characteristics

The demographic characteristics of study subjects are presented in Table 1. In this study, 63.3% of the respondents were male, and 74.5% of the respondents identified themselves as heterosexual. Around half of the respondents (50.2%) ranged in age from 19 to 35 years old (mean = 35.47, *SD* ± 8.51). Considering ethnicity, 63.3% of them were Balinese. Over half of the respondents were Hindu (58.6%) and had completed senior high school (52.6%). Approximately two-thirds (67.4%) reported being diagnosed with HIV between the ages of 19 and 35, and 65.6% reported knowing the diagnosis for more than 2 years. More than two-thirds (68.9%) of them reported living with family members.

3.2 | HIV stigma experience

Table 2 demonstrates the mean scores of overall HIV stigma and its subscales. The mean score of overall stigma was 42.88, with a *SD* of ±17.59 and scores ranging from 7.81 to 87.13. Among the four subscales, self-acceptance had the highest mean score (mean = 73.57, *SD* ± 20.34) and social relationships had the lowest (mean = 16.73, *SD* ± 17.43). Of the 28 items of the self-acceptance subscale, the three with the highest mean scores were “feeling uncomfortable with telling others about their HIV status” (mean = 85.50, *SD* ± 24.25); “feeling uncomfortable with talking about HIV with family” (mean = 81.75, *SD* ± 27.00); and “considering it important to keep their HIV status a secret from co-workers” (mean = 67.75, *SD* ± 37.50). Conversely, the three lowest mean scores in the social relationship subscale corresponded to “feeling abandoned by their family due to their HIV status” (mean = 13.50, *SD* ± 25.00), “nurses and doctors treating PLWH as if they are contagious” (mean = 9.75, *SD* ± 18.75), and “nurses and doctors disliking providing care for PLWH” (mean = 6.50, *SD* ± 16.00). In addition, the comparison between demographic characteristics variables and HIV stigma experience resulted in *p* values ranging from .05 to .97, which means no statistically significant difference between the groups was detected (*p* > .05).

TABLE 1 Demographic characteristics and HIV stigma experience of people living with HIV (N = 215)

Demographic characteristic	n	%	Mean ± SD	χ^2 ^a / Z ^b	p
Age (years)					
(Min = 19; Max = 64)			35.47 ± 8.51	2.26	.32
19–35	108	50.2	43.92 ± 16.92		
36–55	103	47.9	42.21 ± 18.33		
56–64	4	1.9	32.08 ± 15.02		
Gender				–0.59	.27
Male	136	63.3	42.24 ± 17.10		
Female	79	36.7	43.98 ± 18.46		
Sexual orientation				4.63	.09
Heterosexual	160	74.5	42.10 ± 18.00		
Homosexual	33	15.3	48.97 ± 16.21		
Bisexual	22	10.2	39.42 ± 14.95		
Religion				0.77	.97
Hinduism	126	58.6	43.00 ± 18.90		
Islam	55	25.6	43.44 ± 16.12		
Protestant Christianity	20	9.3	41.12 ± 17.56		
Buddhism	8	3.7	39.94 ± 12.91		
Catholicism	4	1.9	42.71 ± 9.58		
Other	2	0.9	49.53 ± 1.42		
Race/ethnicity				2.78	.59
Balinese	136	63.3	42.89 ± 18.47		
Javanese	52	24.2	42.85 ± 15.75		
Betawi/Jakarta	2	0.9	33.34 ± 0.41		
Chinese	3	1.4	31.12 ± 1.53		
Other (e.g., people from Sumatra, Kalimantan, Sulawesi, Maluku, Nusa Tenggara Islands, etc.)	22	10.2	45.34 ± 17.94		
Level of education				5.48	.24
No education	1	0.5	^c		
Primary school	19	8.8	39.02 ± 15.03		
Junior high school	46	21.4	43.25 ± 18.05		
Senior high school	113	52.6	41.63 ± 18.05		
Undergraduate/post-graduate	36	16.7	47.79 ± 16.23		
Employment status before HIV diagnosis				3.21	.52
Unemployed	16	7.4	43.86 ± 19.81		
Employed					
Self-employee/business owner	37	17.2	39.93 ± 17.73		
Private sector employee	128	59.5	43.33 ± 17.27		
Government employee	7	3.3	52.33 ± 20.80		
Other profession	27	12.6	41.76 ± 17.03		
Employment status after HIV diagnosis				0.55	.96
Unemployed	25	11.6	44.60 ± 17.38		
Employed					
Self-employee/business owner	49	22.8	41.80 ± 17.64		

(Continues)

TABLE 1 (Continued)

Demographic characteristic	n	%	Mean ± SD	χ^{2a}/ Z^b	p
Private sector employee	112	52.1	42.79 ± 17.70		
Government employee	6	2.8	44.94 ± 17.91		
Other profession	23	10.7	43.22 ± 18.43		
Age at HIV diagnosis				7.60	.05
≤ 18	4	1.9	30.43 ± 10.90		
19–35	145	67.4	42.83 ± 17.11		
36–50	59	27.4	45.49 ± 18.47		
51–64	7	3.3	29.06 ± 16.12		
Duration after HIV diagnosis				3.49	.17
< 1 year	42	19.5	45.58 ± 18.04		
1–2 years	32	14.9	37.91 ± 17.75		
> 2 years	141	65.6	43.20 ± 17.32		
Place of residence				−0.39	.34
Rural	64	29.8	43.80 ± 17.75		
Urban	151	70.2	42.49 ± 17.57		
Living with whom				2.08	.55
Alone	37	17.2	46.48 ± 16.93		
Family	148	68.9	42.32 ± 17.64		
Friend(s)	8	3.7	41.52 ± 18.25		
Spouse	22	10.2	41.12 ± 18.52		

Note: p value of significance at <.05.

^aKruskal-Wallis test of demographic characteristics and HIV stigma.

^bMann-Whitney Test of demographic characteristics and HIV stigma.

^cThe data could not be computed because there was a only single item.

TABLE 2 Range, mean, SD and level of HIV stigma experience (N = 215)

Subscale	Range	Mean	SD	Level
Stereotypes	0.00–93.75	34.91	21.89	Low
Disclosure concerns	0.00–100.00	46.32	29.35	Low
Social relationships	0.00–71.43	16.73	17.43	Low
Self-acceptance	12.50–100.00	73.57	20.34	High
Total stigma	7.81–87.13	42.88	17.59	Low

3.3 | HIV stigma management strategies

The three most used strategies reported by the participating PLWH were prayer (70.7%), positive thinking (70.2%), and keeping their HIV status a secret (66.0%). Meanwhile, the three least used strategies were forgiving one's spouse (4.1%), forgiving oneself (8.3%), and being selective when choosing friends or a community in which to live or work (13.5%) (Table 3). The most frequently reported reasons for managing HIV stigma were to alleviate and/or avoid stress (68.8%); to live like "normal"

people, who do not have HIV (57.7%); and to transform negative thoughts to positive ones (55.3%). Furthermore, the top three most effective stigma management strategies were prayer or participating in spiritual practices (28.8%); positive thinking (26.5%); and working or finding some activity to occupy oneself with (15.8%). Conversely, the strategies rated as the least effective were staying alone in a quiet room or place (21.9%); sharing one's story with or seeking support from friends (16.7%); and sleeping (6.5%).

4 | DISCUSSION

This is the forerunner study on HIV stigma experience and HIV management strategies with a sufficient number of PLWH from Bali, Indonesia. It revealed that HIV stigma exists in Indonesia. The overall transformed mean score of HIV stigma was at a low level. Further comparison between each group of demographic characteristics and HIV stigma did not find any significant differences. The findings indicated that PLWH, regardless of

TABLE 3 Stigma management strategies employed by people living with HIV (N = 215)

Stigma management strategy	n (%)	n (%) ^a	n (%) ^b
Prayer	152 (70.7)	62 (28.8) ¹	
Positive thinking	151 (70.2)	57 (26.5) ²	
Keeping HIV status a secret	142 (66.0)		
Adherence to treatment	135 (62.8)		
Preoccupation with other things or activities	133 (61.9)		
Trying to live life and coming to terms with being a person living with HIV	132 (61.4)		
Working	127 (59.1)	34 (15.8) ³	12 (5.6) ⁴
Behaving like “normal” people who do not have HIV	125 (58.1)		
Hanging out or traveling	124 (57.7)	15 (7.0) ⁵	
Pursuing a hobby (doing favorite daily activities)	114 (53.0)	21 (9.8) ⁴	
Looking to the future	113 (52.6)		
Focus on the here and now	94 (43.7)		
Practicing silence and solitude	93 (43.3)		
Seeking support from healthcare providers	93 (43.3)		
Hiding antiretroviral drugs or changing their package labels	91 (42.3)		
Seeking support from the family	83 (38.6)	11 (5.1) ⁷	
Sleeping enough	82 (38.1)		14 (6.5) ³
Trying to not care about what people say or do	74 (34.4)		
Seeking support from one's spouse	69 (32.1)	4 (1.9) ⁸	
Abstaining from the discussion of topics related to HIV	67 (31.2)		
Doing good or behaving well in line with the concept of <i>Karma</i>	61 (28.4)		
Sharing information with or educating others about HIV	53 (24.7)		
Ignoring negative feelings	52 (24.2)		
Staying alone in a quiet room or place	50 (23.3)		47 (21.9) ¹
Seeking the support of a friend	49 (22.8)	11 (5.1) ⁶	36 (16.7) ²
Accepting whatever happens as the will of God	46 (21.4)		
Joining the HIV community	46 (21.4)		
Feeling oneself to be lucky and better than others in some ways	44 (20.5)		
Reading holy books	44 (20.5)		
Relocation—moving from one area to another	43 (20.0)		
Seeking information from healthcare providers	42 (19.5)		
Trying to be nice to people (doing good to others)	42 (19.5)		
Meditation or <i>Yoga</i>	40 (18.6)		
Changing the topic when people discuss HIV	35 (16.3)		
Creating ulterior reasons (hiding the true reasons) to explain their health condition and/or illness	29 (13.5)		
Being selective when choosing friends or the community where to live or work	29 (13.5)		
Forgiving oneself	18 (8.3)		
Forgiving one's spouse/partner	9 (4.1)		

Note: ¹⁻⁸Number for rank: both the most and the least effective strategies.

^aMost effective strategy.

^bLeast effective strategy with 106 respondents (49.3%) choosing “no ineffective strategies were identified” or all strategies being effective to some extent.

demographic differences, shared similar internalized stigma experiences.

Similar to the present study, Gohain and Halliday (2014) reported a low level of overall stigma (mean = 41.07, $SD \pm 16.66$). However, the self-acceptance subscale had the highest mean score of the four subscales. This reflects that the respondents had not yet accepted themselves as PLWH. It is known that PLWH tend to feel guilty and miserable after their HIV diagnosis (Donnelly et al., 2016; Karamouzian, Akbari, Haghdoost, Setayesh, & Zolala, 2015), which makes it difficult for them to accept their HIV status. According to Sayles et al. (2008), stigma occurs when the person fails to conform to cultural norms and is identified as a member of a deviant group, which leads to that person assuming a “spoiled identity” in the community. In Indonesia, sexuality is considered a taboo issue. Religious teachings can be a contributing factor toward elevating the level of HIV stigma (Waluyo et al., 2015). Most Indonesians claim to have a certain religious faith, which prohibits homosexuality, same-sex marriage, extramarital sex, and drug use (Waluyo et al., 2015). In addition, Indonesians have the perception that HIV/AIDS is a curse-related disease for sinful persons like PLWH (Irmayati, Yona, & Waluyo, 2019). A self-perception of deviating from social and cultural norms may explain why our respondents stigmatized themselves (Waluyo et al., 2015). Contracting HIV infection may make them feel sinful and unfaithful to God (Sulung & Asyura, 2019).

The social relationships subscale yielded the lowest mean score; furthermore, three items from this subscale had the lowest mean scores. This reflects the fact that the respondents felt less stigmatized by healthcare providers and reported having a good relationship with their nurses and doctors. An explanation for this could be that HIV health services in our study settings are isolated from other OPDs or clinics, so respondents could have the opportunity to engage in a more comfortable interaction and build healthier relationships with healthcare providers. The findings from this study are inconsistent with those of previous studies, which have reported PLWH experiencing discrimination from spouses, healthcare providers, and society at large as well as tending to avoid family activities (Dos Santos, Kruger, Mellors, Wolvaardt, & van der Ryst, 2014; Fazeli et al., 2017; Karamouzian et al., 2015; Mhode & Nyamhanga, 2016; Stutterheim et al., 2014).

In order to reduce stigma attached to HIV/AIDS, the participating PLWH attempted to manage it as best they could. Of the 38 stigma management strategies, prayer was the most common and effective strategy. The majority of Indonesians, regardless of the religious background, believe in the existence of God and His power

(Ropi, 2017). Sulung and Asyura (2019) found that PLWH in Indonesia use prayer as a strategy to get closer to God and forsake sexual promiscuity. While praying, PLWH feel a peace of mind, tend to be more accepting of their HIV status and their illness, and become more willing to access HIV-related healthcare services (Tang & Chen, 2018). Furthermore, positive thinking was the second most used strategy by the respondents to manage HIV stigma. Thinking positively may lead to positive coping strategies, wherein positive coping strategies tend to have a positive impact on health outcomes among PLWH (Kumar, Mohanraj, Rao, Murray, & Manhart, 2015). Positive thinking strategies have been developed to enhance problem-solving skills, improve adherence to treatment, and decrease internalized HIV stigma among young adults in the United States (Mimiaga et al., 2019).

In addition, keeping one's HIV status a secret was rated as the third-highest used strategy in managing HIV stigma. The Indonesian values of “*gotong royong*” or mutual assistance and “*menyama braya*” or good social interaction among people, particularly among the Balinese, might be the safest way to avoid HIV stigma. PLWH may feel fearful that others would notice their HIV status through the physical changes as a result of their illness. They tend to worry about being discriminated against in the community (Albright & Fair, 2018; Arrey, Bilsen, Lacor, & Deschepper, 2015). Hence, PLWH prefer to keep their HIV status a secret. These findings corroborated those reported by a previous study by Arrey et al. (2015) in that the reason PLWH keep their HIV status a secret is due to the fear of stigma and discrimination, rejection, shame, violence, abandonment, and fear of disrupting relationships. In South Africa, keeping one's HIV status a secret is primarily achieved through social withdrawal and self-isolation as ways to cope with HIV stigma (Judgeo & Moalusi, 2014).

In contrast, forgiving one's spouse or oneself was reported as the least used management strategy in this research. Forgiveness is a path to relieve one's feelings of guilt through a focus on forgiving the “who”, which is central to forgiveness (Breitbart, 2018). In light of the high-level score of the self-acceptance subscale, it could be deduced that our respondents internalized stigma toward themselves. They perceived themselves as failing to adhere to cultural norms, which, in turn, led them to adopt a “spoiled identity”. Moreover, since they felt shame and were uncomfortable with their HIV status (Sayles et al., 2008), they might have found it difficult to forgive themselves and/or their spouse if they were the source of their HIV infection.

The respondents in this study reported that the most common reason to manage the HIV stigma they faced was their intention to decrease stress. Stress among

respondents in this study may derive from their inability to satisfy society's expectations, which, in turn, leads to a heightened psychological burden (Florum-Smith & De Santis, 2012). Furthermore, the least effective strategy was staying alone. Staying alone might lead one to recall past memories related to the time when the PLWH realized they had contracted HIV. As a consequence, negative feelings could occur and lead to psychological stress due to feeling lonely (Miller et al., 2016; Peltzer, Ogawa, Tusher, Farnan, & Gerkovich, 2017).

Concerning the social relationship subscale, a good social relationship was found between our PLWH and healthcare providers, which differs from the findings of other studies. It was observed that the HIV health services were isolated from the other OPDs or clinics in this study's settings enabling the respondents to engage in a comfortable interaction with the healthcare providers. Furthermore, the uniqueness of the Balinese culture was reflected in the PLWH living in Bali. It is customary and even expected for one to manage a hardship such as stigma independently, hence the finding of 38 stigma management strategies employed by our participating PLWH, which is a rare occurrence when compared to other studies.

4.1 | Limitations of the study

The SMSC was obtained from the results of a qualitative preliminary study and developed by the researchers into a checklist form. Thus, it may be limited in measuring the target construct of stigma management. It is, therefore, recommended that future studies should examine the construct validity of the SMSC employed in this survey.

5 | CONCLUSION AND IMPLICATIONS

HIV stigma exists among PLWH in Bali, Indonesia. Self-acceptance is a major issue, with PLWH feeling uncomfortable telling anyone about their HIV status and being unwilling to forgive oneself and/or one's spouse for contracting the infection. Prayer was the most common strategy used to manage stigma and the most effective strategy to get closer to God. Religious faith plays a key role in both internalized stigma as well as stigma management. Therefore, nurses' responsibilities are twofold; they concern PLWH as well as the society at large. Public health education interventions about HIV/AIDS, which emphasize human values and tolerance in the society specifically, are necessary for the prevention of HIV stigma in the community. Finally, the development of

faith-based stigma management interventions emphasizing forgiveness and self-acceptance as well as the study of their effectiveness are recommended.

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CONFLICT OF INTEREST

The authors declare no conflicts of interest.

AUTHOR CONTRIBUTIONS

All authors contributed to this manuscript. Study conception and design: NAJR and KN. Data collection: NAJR. Data analysis and interpretation: NAJR and KN. Drafting of the article: NAJR and KN. Critical revision of the article: NAJR and KN. Both authors approved its final version for submission.

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