



**Experience and Management of Stigma Among Persons Infected
With HIV in Bali, Indonesia**

Nyoman Agus Jagat Raya

**A Thesis Submitted in Partial Fulfillment of the Requirements for the
Degree of Master of Nursing Science in Adult and Gerontological
Nursing (International Program)
Prince of Songkla University
2019**

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Thesis Title Experience and Management of Stigma Among Persons Infected With HIV in Bali, Indonesia

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I hereby certify that this work has not been accepted in substance for any degree, and is not being currently submitted in candidature for any degree.

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ABSTRACT

A descriptive cross-sectional study was conducted to describe the level of HIV stigma experience and management strategies among persons infected with HIV (PIWH) in Bali, Indonesia. Two-hundred and fifteen respondents selected from four locations were enrolled from March to May 2019. The Demographic Characteristics Form Persons Infected With HIV (DCFPIWH), the 28-Item Internalized HIV Stigma Scale, and the Stigma Management Strategies Checklist (SMSC) developed by the researcher were used to gather the data. Descriptive statistics were used for data analysis.

A moderate level of HIV stigma experience was reported among PIWH respondents ($M = 42.88, SD \pm 17.59$). The highest mean score from the content of items was in the self-acceptance subscale ($M = 85.50, SD \pm 24.25$) and the lowest was in the social-relationships subscale ($M = 6.50, SD \pm 16.00$). In addition, among 37 stigma management strategies, the three highest percentage which most often used by PIWH were praying (70.7%), positive thinking (70.2%), and keeping HIV status a secret (66.0%). The most common reason to manage stigma was to decrease and/or avoid stress (68.8%) through self-study to manage stigma and support from friends, family members, spouses, and health care providers. The majority of the respondents

(96.3%) stated having effective stigma management strategies and 65.6% of respondents expressed being satisfied with their stigma management strategies. The first most effective strategy was praying (28.8%) and the first least effective was staying alone (21.9%).

Imply the importance of understanding stigma experience among PIWH particularly in such a multi-ethnic and religion country as Indonesia. This understanding is believed to be a significant attempt to stigma management strategy. Additionally, in order to avoid increasing stigma towards PIWH, maintaining the confidentiality of PIWH's HIV status is of a great importance. Strategies to manage stigma could involve the implementation of religious teachings. Finally, future HIV stigma experience and management strategies studies demand further in-depth exploration, primarily when associated with PIWH's religion and culture.

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ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral
CD4	Cluster of Differentiation 4
DCFPIWH	Demographic Characteristics Form Persons Infected With HIV
HIV	Human Immunodeficiency Virus
IDU	Injection Drug User
MSM	Men who have Sex with Men
OPD	Outpatient Department
PIWH	Persons Infected With HIV
SMSC	Stigma Management Strategies Checklist
SMSOQ	Stigma Management Strategies Open Questions
STI	Sexually Transmitted Infections
UNAIDS	The Joint United Nations Programme HIV/AIDS
VCT	Voluntary Counseling and Testing
WHO	World Health Organization

Chapter 1

Introduction

This chapter presents the background and significance of the problem, the objectives, research questions, conceptual framework, definition of terms, scope, and significance of the study. The details for each part are as follows:

Background and Significance of the Problem

Human Immunodeficiency Virus (HIV) infection and Acquired Immunodeficiency Syndrome (AIDS) was recognized as a truly emerging disease in 1981 (Fauci, 2006; Morens & Fauci, 2013). Due to its pandemic, HIV infection and its impact have been one of the main public health concerns globally. The 2018 Joint United Nations Programme 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 were 36.9 million, and the number of people who died due to AIDS was around 940,000 in 2017. Besides, 20.9 million people who were HIV-infected were on antiretroviral therapy (ART) in June 2017 (UNAIDS, 2017). Meanwhile, Indonesia is one of the countries where the HIV epidemic is rapidly increasing; it ranked second (23%) for AIDS-related deaths among Asia-Pacific countries in 2017 (UNAIDS, 2018). Data collection about HIV/AIDS in Indonesia began in 1987; the first HIV infection case was recorded in Bali. In 2016, there were 232,323 HIV infected persons nationwide cases; 86,725 AIDS cases, and 14,608 deaths due to AIDS (Directorate General of Disease Control and Environmental Health, Ministry of Health, Republic of Indonesia, 2017).

Apart from the HIV epidemic as a global public health challenge, HIV stigma is a phenomenon that has been commonly reported in many countries in the world (Stuenkel & Wong, 2013). Persons infected with HIV (PIWH) in Canada described their stigma experience as a feeling of shame and guilt. They blamed themselves as an infected person and feared to disclose their HIV status (Donnelly et al., 2016). Similarly, a study by Arnold, Benton, Loveluck, Skipper, and Sprague (2016) in Michigan, United States found that 80% of PIWH experienced negative feelings towards themselves. In India, heterosexual men with HIV infection reported a high level of negative attributions toward themselves, whereas heterosexual women reported a high level of experiencing stigma (Malave, Ramakrishna, Heylen, Bharat, & Ekstrand, 2014). Similarly, stigma was a highly discrediting and traumatic experience among PIWH in Lesotho, Swaziland, Malawi, South Africa, and Tanzania (Greff et al., 2008).

HIV stigma affects the physical and psychological aspects of PIWH's health (Donnelly et al., 2016; Earnshaw & Chaudoir, 2009). In China, men who have sex with men (MSM) and infected with HIV were reported to have high rates of depression and employing negative coping mechanisms (Li, Hsieh, Morano, & Sheng, 2016). Furthermore, HIV stigma among PIWH leads to negative health outcomes such as an increased risk of opportunistic infections (Li, Morano, Khoshnood, Hsieh, & Sheng, 2018) and mental health disorders (Smith & Santis, 2012). Similarly, non-adherence to ART is a significant problem (Li, Morano, Khoshnood, Hsieh, & Sheng, 2018; Smith & Santis, 2012), often resulting from such patients opting to not access health services, can also lead to losing one's employment, thereby increasing the risk of being forced to relocate from respective housing. Furthermore, the risk for physical

violence and/or verbal abuse (Santos, Kruger, Mellors, Wolvaardt, & Ryst, 2014; Smith & Santis, 2012), and spread of HIV transmission (Ruffell, 2017; Smith & Santis, 2012) are commonplace among PIWH.

As HIV/AIDS impacts PIWH negatively, they attempt to manage the HIV stigma. Stigma management is a method to reduce or prevent the impact of HIV stigma (Sengupta et al., 2011). PIWH often try to build positive peer networks as a strategy to manage their experiences related to HIV stigma when they feel shame, guilt, and worthlessness (Kumar, Mohanraj, Rao, Murray, & Manhart, 2015). Similarly, Rael et al. (2017) reported that PIWH use strategies such as HIV disclosure control, preemptive disclosure of HIV status, educating others even for oneself about HIV, viewing HIV as a manageable condition, and seeking support from family members and close friends to manage HIV stigma. A qualitative study by Mhode and Nyamhanga (2016) revealed that spiritual devotion, accepting the condition and illness, concealing being on ART to other people, sharing experiences as PIWH, and preemptively disclosing the HIV status were ways used to manage stigma among PIWH. Similarly, in another study from Nepal, it was revealed that “keeping a secret” was popular as a strategy to manage the stigma; this involved prohibiting friends to visit the PIWH’s home for fear that they would find out the person was HIV positive due to the presence of medicines or documents related to HIV at home (Aryal, 2017).

In Indonesia, HIV stigma and discrimination toward PIWH is common (Merati, Supriyadi, & Yuliana, 2005; Mutahar, Najmah, & Yenni, 2011). Indonesians believe HIV is punishment from God due to their bad behavior or sins, especially regarding promiscuous sexual behavior (Ibrahim & Songwathana, 2009). A study about the Indonesians’ attitude regarding stigma reported that 58% of participants

stigmatized PIWH or had a negative attitude toward them (Mutahar, Najmah, & Yenni, 2011). Furthermore, HIV stigma among health care providers toward PIWH has been reported. In Aceh, Indonesia, health care providers were found to have a high-level stigma toward PIWH (Harapan et al., 2015). Likewise, an attitude categorized by a high level of HIV stigma has reported among nurses in Indonesia (Waluyo, Culbert, Levy, & Norr, 2015).

In Indonesia, studies on HIV stigma as experienced by PIWH are scant. Previous research on HIV stigma in Indonesia has focused on prisoners with HIV (Culbert et al., 2015; Komalasari, 2012). A mixed-method study by Culbert et al. (2015) revealed some contextual factors regarding stigma among HIV-infected prisoners; they tended to be labeled as drug users or drug offenders, seldom had family visits, anticipated stigma due to receiving minimal social support, and a heightened individual experience and perception of HIV stigma. Moreover, the 2012 Komalasari exploratory study following the qualitative approach revealed that, in such a population, there was a power context, wherein the dominant group in prison propagated stigmatization toward HIV prisoners due to some of them could not hide their HIV status in prison.

Meanwhile, PIWH living in the community and those imprisoned may differ considerably regarding their HIV stigma experiences. HIV-positive prisoners might experience a double stigma—being a prisoner and also a person with HIV—whereas PIWH living in the community that might have a different level of stigma due to their ability to conceal the HIV status. A preliminary study by Aggarwal et al. (2018) in Bandung, Indonesia reported that 64% of PIWH felt worthless and thought that they did not deserve to live. Moreover, a qualitative study by Merati, Supriyadi, and

Yuliana (2005), who explored HIV discrimination in Bali and Jakarta, also mentioned that PIWH living in the community received stigma from health care providers and their workplace, which compounded the negative effects of their disease.

Furthermore, there are limited studies described stigma management strategies among PIWH. A few studies have focused on stigma reduction interventions that were navigated by health care providers (Suyanti, Keliat, & Daulima, 2018).

However, PIWH need to manage the HIV stigma by themselves and independently as most of them prefer to keep their HIV status confidential. Since Indonesia's population is diverse in terms of ethnicity and religion, the way PIWH perceive and manage stigma might differ from that of other countries in the world. Therefore, a descriptive study was conducted to describe the level of HIV stigma experience and stigma management strategies among PIWH. The implications of the study could be that the evidence obtained through it might be fundamental to the development of nursing care programs for PIWH.

Objectives of the Study

There were two main objectives of this study:

1. To describe the level of stigma experienced by persons infected with HIV in Bali, Indonesia.
2. To describe the stigma management strategies used by persons infected with HIV in Bali, Indonesia.

Research Questions of the Study

There were two research questions this study aimed to answer:

1. What is the level of stigma experienced by persons infected with HIV in Bali, Indonesia?
2. What are the stigma management strategies used by persons infected with HIV in Bali, Indonesia?

Conceptual Framework of the Study

The conceptual framework of this study was built upon the concept of internalized HIV stigma by Sayles et al. (2008) and the Symptom Management Model (SMM) by Dodd et al. (2001).

Sayles et al. (2008) conceptualize internalized HIV stigma as a social process where the individual is identified as a member of a deviant group, and the internalized stigma impacts that individual in some way. Sayles et al. (2008) also define internalized HIV stigma as an experienced or perceived stigma by an individual who is being stigmatized related to the treatment and/or other aspects of HIV infection including the socio-demographic aspect. Besides, internalized 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 PIWH. Disclosure concerns reflect worries of PIWH 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 PIWH in social life and their effect to personal relationships with

family members, close friends, and health care provider. Self-acceptance connotes how comfortable the person infected with HIV is with his/her HIV diagnosis.

In addition to the concept of HIV stigma, the Symptom Management Model (SMM) by Dodd et al. (2001) was adopted to guide the exploration of stigma management among PIWH. According to Dodd et al. (2001), the three dimensions of SMM comprise symptom experience, symptom management, and outcomes. However, this study focuses only on symptom management. Here, symptom management was defined as the strategies an individual uses to prevent or manage a given symptom; this entails the specification of what (the nature of the strategy), when (time), where (place/source), why (reason), how much/how often (dose of intervention), to whom (target), and how (delivery) (Dodd et al., 2001).

Figure 1 depicts the conceptual framework derived from conceptualization of the internalized HIV stigma as it regards one's experience with HIV stigma (Sayles, et al., 2008), which also adopted a dimension of SMM, namely the stigma management strategy (Dodd et al., 2001).

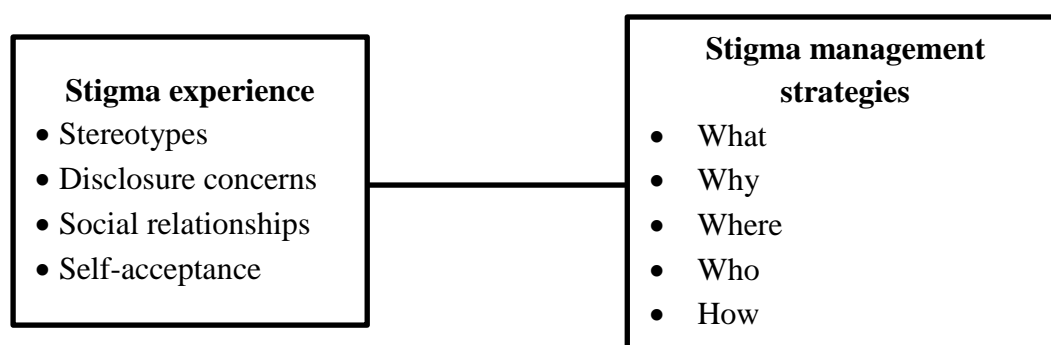


Figure 1. Conceptual Framework of This Study

Definition of Terms

Stigma experience. Stigma experience refers to the perception of stigma as experienced by PIWH. It is based on the internalized HIV stigma, which consists of stereotypes, disclosure concerns, social relationships, and self-acceptance. Stigma experience was measured using the 28-Item Internalized HIV Stigma Scale developed by Sayles et al. (2008). This tool was translated into Bahasa Indonesia. Higher scores refer to higher stigma levels.

Stigma management strategies. Stigma management strategies refer to actions or strategies PIWH use to minimize the stigma experience. These strategies include the specification of stigma management strategy (*What*), the reason for using stigma management (*Why*), source of information (*Where*), person who helped in managing the stigma (*Who*), and the most and the least effective stigma management strategy (*How satisfaction with and effectiveness of strategy*). Stigma management strategies were measured using the Stigma Management Strategies Checklist (SMSC) developed by the researcher. A higher percentage referred to a larger number of stigma management used by PIWH.

Scope of the Study

This descriptive study was undertaken to describe the level of HIV stigma experienced by PIWH and the stigma management strategies they employ to cope with that stigma. This study was conducted in three hospitals and a private clinic in Bali, Indonesia from March to May 2019.

Significance of the Study

The knowledge obtained from this study could contribute to increase the awareness of nurses, other health care providers, educators, and researchers regarding the current situation related to the experience of stigma among PIWH and to provide a list of stigma management strategies utilized by PIWH in order to deal with the negative effects of stigma. Also, this study's descriptive data could be used to develop appropriate interventions for PIWH aimed at preventing or minimizing HIV stigma. Moreover, such evidence-based data could inform the nursing curriculum that deals with HIV stigma and its management. Furthermore, the results of this study could be used as basic data to guide or develop further research regarding the topic of HIV stigma in Indonesia.

Chapter 2

Literature Review

This chapter presents the literature review that covers the concepts of and evidence regarding stigma experience and stigma management strategies among PIWH. The current situation of HIV and care related to it in Bali, Indonesia will also be explained in this chapter. The detailed outline of the literature review undertaken in this research is presented as follows:

1. Stigma as Experienced by Persons Infected With HIV
 - 1.1 Concept of stigma
 - 1.2 Concept of HIV stigma
 - 1.3 Internalized HIV stigma
 - 1.4 Measurement tools of HIV stigma
2. Stigma Management Strategies Used by Persons Infected With HIV
 - 2.1 Concept of stigma management
 - 2.2 Current evidence of stigma management by persons infected with HIV
 - 2.3 Factor related to stigma experience and management among persons infected with HIV
3. HIV Situation and Care in Bali, Indonesia
 - 3.1 HIV epidemic and national programs in Indonesia
 - 3.2 Social response to persons infected with HIV
 - 3.3 Current evidence of HIV stigma in Indonesia
4. Summary of Literature Review

Stigma as Experienced by Persons Infected With HIV

The experience of stigma among PIWH is a subjective matter that appears after being diagnosed with HIV infection. Persons who are diagnosed HIV-positive have the may face stigma from their family, close friends, and the society at large. The stigma attached to PIWH results from the general held belief that one's behaviors leading to HIV transmission deviate from the norms of the society. This section will be devoted to describing the concepts of stigma in general, HIV stigma, and internalized HIV stigma, as well as the measurement tools of HIV stigma.

Concept of stigma. Many theorists and researchers define stigma in general terms enabling it to inform the background knowledge of many disciplines. Generally, the concept of stigma is derived from Goffman's proposed definition (1963) as the theorist of stigma. This section will describe the definition of stigma, stigma as a social process, types of stigma, and characteristics of stigma.

Definition of stigma. The term 'stigma' is derived from Greek and refers to "bodily sign designed to express something unusual and bad about the moral status of the signifier" (Goffman, 1963, p.1). Goffman (1963) explains that stigma as an attribute has deep discrediting abilities. 'Discrediting' means that people can both create and perpetuate the stigma, whereas 'discreditable' describes the situation of a person with a despicable character (Smith & Santis, 2012). In addition, stigma is a process of socialization where the discredit of people arises from a social belief about one's personality, behavior, and/or illness (Stuenkel & Wong, 2013).

Stigma as a social process. A social process derives from the attributes of the society, which establishes how people are categorized (Goffman, 1963). According to Link and Phelan (2001), stigma as a social process will exist when the characteristics

of stigma co-occur on a power structure. A power structure occurs if the person or group, who enjoys more power in the society, has the chance to stigmatize people; then the stigmatization of the stigmatized occurs, e.g., discrimination (Link & Phelan, 2001). The society's attributes provide the power to stigmatize in areas such as social life activities, economics, and politics. Thus, a power structure on a stigma condition is essential, which is specifically reflected in each type of stigma. Concisely, according to the definition of stigma from Pescosolido and Martin (2015), stigma requires the presence of four components—labeling of the differences; distinguishing human differences through negative attributes in stereotyping; differences described using the terms “us” and “them” that can serve to separate “us” from “them”; and people experiencing discrimination and status loss. All of these things reflect the relationship between the ‘stigmatizer’ and the ‘stigmatized’ in the social process.

Types of stigma. According to Goffman (1963), there are three types of stigma: the stigma of physical deformity, character blemishes, and prejudice. First, the stigma of physical deformity or actual stigma occurs when the expected norm of perfect physical condition is not in accordance with the actual physical condition. The changes in one's physical condition might be due to chronic illness, accident, or aging; they may somehow distinguish the individual from “the common people”. Second, the stigmatizer will judge the stigmatized and influence other people with their behavior. This is called character blemish. Third, prejudice or discrimination that is tribal in origin occurs when one group perceives the features of the race, religion, sociocultural norms or values, or nationality of another group and then compares them with their own socioculturally constructed norms.

Characteristics of stigma. Stigma characteristics include labeling, stereotyping, separating, status loss, discrimination, and prejudice (Link & Phelan, 2001).

Labeling. Labeling is assigning a mark to a person due to that person possessing a characteristic that differ from the “normal” or predominant character of the group. This difference or deviance is ascribed to the person due to the power structures of society (Goffman, 1963). According to Goffman’s theory (1963), labeling is social behavior that gives a label to people who do not conform to a given norm in the society. However, labeling does not only occur to an individual but also to groups, places, organizations, companies, or other social entities (Pescosolido & Martin, 2015).

Stereotyping. The stereotype occurs when the society reacts negative beliefs and attitudes that are assigned to be so by the society (Pescosolido & Martin, 2015; Stuenkel & Wong, 2013). The stereotype has a link with a label, a negative label either in the minds of other persons or the person him-/herself (Link, Yang, Phelan, & Collins, 2004).

Separating. Due to a different character from the other people in the group, separating occur when the “them” out from the circle of “us” in a social group. According to Link and Phelan (2001), the stigmatization occurs when the stigmatized person has thought that he/she to be so different from “us”. They also explained that “them” are immoral and a menace to “us”.

Status loss. The status loss refers to the reduction of the status of the person with an undesirable characteristic in the stigmatizer’s view (Link & Phelan, 2001). Moreover, the status loss is a consequence of devaluation, rejection, and exclusion

from the society that leads to unequal outcomes (Mahajan et al., 2008; Link, Yang, Phelan, & Collins, 2004).

Discrimination. Discrimination is an act or behavior resulting from the negative judgment of the group toward another person or group (Smith & Santis, 2012). Discrimination is divided into two kinds—individual and structural discrimination. Individual discrimination involves the labeling, stereotyping, and stigmatization of someone perceived to be deviant in some way by another person, who identifies with what is considered the societal norm regarding a given characteristic. On the other hand, structural discrimination is institutional racism or persecution, which sets off the disadvantageous manner with which one person treats another (Link & Phelan, 2001).

Prejudice. Prejudice is the justification of negative beliefs and attitudes of person toward another person categorized by a stereotype (Pescosolido & Martin, 2015). The form of judgment in prejudice is against a group (Smith & Santis, 2012).

To sum up, stigma is a mark aimed at discrediting a person by means of labeling, stereotyping, separating, causing status loss, discriminating, and prejudicing those associated with a norm deviation as it regards social life. If the person has the same character, condition, and situation with the other persons, then the stigma will not occur in that group. Regardless, stigma will occur as a social process if a society's norms and beliefs are not followed by its members properly.

Concept of HIV stigma. Based on the concept of stigma, researchers have developed the concept of HIV stigma. In this study, the explanation of the concept of HIV stigma consists of the definition of HIV stigma, the application of Goffman's theory of stigma to HIV stigma, and the discussion of the types of HIV stigma.

Definition of HIV stigma. HIV stigma is a collection of negative attitudes and beliefs people have toward PIWH, which may effect the existence of deleterious internal beliefs among or actions undertaken by PIWH (Smith & Santis, 2012). The main idea of HIV stigma is derived from the social process of stigma where internalized HIV stigma occurs due to cultural norms not being observed by a deviant group in the community (Sayles et al., 2008). Earnshaw and Chaudoir (2009) developed the HIV stigma framework and defined internalized HIV stigma as negative beliefs and feelings toward PIWH. Moreover, Parker and Aggleton (2003) also maintained that HIV stigma is a ‘significantly discrediting’ attribute in society due to the associating negative social responses toward PIWH. Similarly, Sengupta et al. (2010) define HIV stigma as mostly an act of discrimination by non-stigmatized persons toward PIWH. Therefore, the definition of HIV stigma is a negative attitude and societal response from purposed to discredit PIWH as a deviant group in the community, which may cause internal negative beliefs or feelings among PIWH.

Application of Goffman’s stigma theory to HIV stigma. Goffman’s theory of stigma (1963) can be applied to stigma experienced among PIWH. Three situations can describe the application of Goffman’s stigma theory to HIV stigma. First is the actual stigma. PIWH suffer from physical symptoms due to their HIV infection or the side effects of their antiretroviral medication, which could appear rash, weight loss, diarrhea, etc. This may enable people around the PIWH to notice the person may have some condition related to HIV based on their physical appearance, which could trigger the process of stigma against that person. Second, character blemishes may be assigned when a person has AIDS and is a homosexual. For example, the society may correlate homosexuality to HIV transmission. The character of gay persons may be

tarnished, since homosexuals as a group may be perceived to be responsible for the spread of HIV due to the previous highest number of HIV transmissions being associated with the homosexual group, specifically the gay lifestyle. It seems like a double stigma is attached to this group. The third is prejudice that is tribal in origin. For example, health care providers in HIV clinics may treat PIWH in a different way or prejudice them due to them having different cultural norms, religion, age, race, and/or nationality.

Types of HIV stigma. Earnshaw and Chaudoir (2009) identified three types of HIV stigma: enacted, anticipated, and internalized stigma. Enacted stigma is the actual experience of prejudice and discrimination perpetrated by the community; anticipated stigma is the perceived prejudice and discrimination experience the PIWH expect to incur from others in the future; internalized stigma connotes the experience of stigma experienced by PIWH that is expressed in negative feelings and beliefs toward themselves. The higher the enacted stigma experience the higher the psychological distress and negative impact on well-being; as the of anticipated stigma increases, the rate of HIV status disclosure decrease due to fear of social rejection; and a high level of internalized stigma experience will lead to poor psychological well-being (Earnshaw & Chaudoir, 2009).

Sayles et al. (2008) developed a concept that focuses on internalized HIV stigma; it was based on the qualitative analysis of data obtained from their focus group. First of all, they found the domains of internalized HIV stigma—stereotypes and confronting blame of HIV; confronting “fear of contagion”; disclosure negotiation due to stigmatized role; and renegotiation of social relations in the community. Furthermore, after developing and assessing the tool, they found that self-

acceptance relates to the person's comfort with HIV, whether the PIWH accepts being an HIV person. Subsequently, the "fear of contagion" is deleted due to the collapse of social relationships. Thus, the dimension of internalized HIV stigma by Sayles et al. (2008) consists of stereotypes, disclosure concerns, social relationships, and self-acceptance.

A study by Sengupta et al. (2010) developed a conceptual model for HIV stigma, and it revealed the theoretical construct of HIV stigma. Here, the PIWH perceived, experienced, vicarious, and felt the normative stigma as HIV stigma. This conceptual model described four types of HIV stigma: perceived stigma as an experience of PIWH feeling being negatively regarded by the community, family, partners, or friends due to their HIV status; experienced stigma through the rejection received in areas such as health care, employment, education, or isolation from family; vicarious stigma happens when PIWH hear stigmatization stories and they feel like they really are stigmatized; and felt normative stigma is a protective mechanism employed by PIWH against stigma.

According to Smith and Santis (2012), the HIV stigma consists of the external and internal types. External HIV stigma refers to an action from the outside (e.g., community, society, public) toward PIWH in the form of rejection, discrimination, or other negative stigmas, whereas internal HIV stigma refers to a negative feeling, belief, or action, which is adopted by PIWH. Both external and internal HIV stigma have negative consequences. Similarly, external and internal HIV stigma were also mentioned by Chidrawi, Greff, Temane, and Doak (2016), wherein external HIV stigma refers to the outsider stigmatizing PIWH, whereas internal HIV stigma refers to stigma of a PIWH toward oneself.

In conclusion, the types of HIV stigma have been classified differently by different researchers. On the one hand, the study by Smith and Santis (2012) explained two general types of HIV stigma—external and internal. On the other hand, other studies (Earnshaw & Chaudoir, 2009; Sengupta et al., 2010) have identified specific types of HIV stigma such as enacted, anticipated, internalized, perceived, experienced, vicarious, and felt normative. However, the meaning of these types of HIV stigma could fall under the category of internalized HIV stigma and, as Sayles et al. (2008) have, be described as HIV stigma experiences.

Internalized HIV stigma. Sayles et al. (2008) explained that internalized 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. This experience is then internalized by the person as HIV stigma. The subscales of internalized HIV stigma include stereotypes, disclosure concerns, social relationships, and self-acceptance.

Stereotypes come from others and concern the individual's perception by the society, coworkers, and medical providers, as well as negative feelings or thoughts about PIWH (Sayles et al., 2008). According to Sayles et al. (2008), stereotypes such as 'HIV is a different illness from other illnesses' can lead PIWH receiving negative reactions from health care providers, e.g., doctor and nurse, underestimated and looked down upon by the society, being considered as undeserving to adopt children or incapable of being a good parent, and being forced to retire from the jobs due to their HIV status. Santos et al. (2014) reported internalized stigma regarding the diagnosis of HIV that manifests like self-blaming (49.2%), feeling guilty (40.9%), having low self-esteem (31.9%), being blamed by others (22.4%), and feeling they

deserve to be punished (10.8%). In addition, stereotyping from health care providers experienced by PIWH in Iran has resulted in care refusal, provision of suboptimal care use of unnecessary precaution when dealing with such patients, and being on the receiving end of verbal and non-verbal blaming (Karamouzian et al., 2017).

Moreover, PIWH in Netherlands have reported experiencing refusal to care (6.9%), being discouraged to seek care (8.8%), unnecessary referrals (5.3%), blame (10.3%), and rude and unkind behavior (10.7%) (Stutterheim et al., 2014).

Disclosure concerns occur when the PIWH worry if others know their HIV status as well as are concerned about their physical changes and responses they get in the HIV clinic when meeting people (Sayles et al., 2008). Santos, Kruger, Mellors, Wolvaardt, and Ryst (2014) revealed that 16.1% of PIWH in South Africa had experienced physical assault due to their HIV status. Moreover, two studies have revealed that concern with the disclosure of one's HIV status was related to internalized stigma (Cuca et al., 2017; Li et al., 2018). Status disclosure seems to have a positive correlation with a higher level of education and a history of opportunistic infections, whereas it appears to correlate negatively with an increase in both age and years since HIV diagnosis (Li et al., 2018). In Canada, PIWH reported feeling tension related to the disclosure of their HIV status due to the fear of experiencing negative reactions from the society; one participant opined that disclosure could be an advantage as it could help receive social support to survive as PIWH (Donnelly et al., 2016).

Social relationships refer to the treatment and reaction of people (outsiders) toward PIWH in social life, which affect the relationship between PIWH and outsiders. One's HIV status may affect personal relationships with family members,

close friends, and health care providers (Sayles et al., 2008). Avoidance between PIWH and outsiders is strongly associated with internalized stigma (Fazeli et al., 2017). Another study in Iran revealed that the avoidance of PIWH by the society was common and a major barrier to their social relationships (Karamouzian et al., 2017). In the Netherlands, 6.1% of 262 PIWH experienced avoidance (Stutterheim et al., 2014). Meanwhile, a study from Tanzania revealed that PIWH experience discrimination from those they have a relationship with, their spouse, and health care workers regarding access to health services and receiving ARV therapy (Mhode & Nyamhang, 2016). Another study from South Africa among 486 PIWH revealed that they were excluded from family activities (15.5%), and were discriminated against (14.6%), and excluded from religious activities (10.3%) (Santos et al., 2014). Moreover, one participant from another study reported having experienced avoidance from a dentist that if the dentist know that a person have HIV, then the dentist would not give an appointment and ask to go somewhere else because the dentist do not help PIWH (Donnelly et al., 2016).

Self-acceptance refers to how comfortable a PIWH is with his/her HIV diagnosis (Sayles et al., 2008). PIWH tend to feel guilty and miserable after their HIV diagnosis (Donnelly et al., 2016; Karamouzian et al., 2017), which makes it difficult for them to accept their HIV status. The ability to move on from feeling guilty and miserable is a prerequisite for their acceptance of themselves as PIWH. Feeling unashamed and comfortable telling others about their HIV status are indicators of self-acceptance. In Canada, PIWH opined feeling shame about their HIV status (Donnelly et al., 2016), whereas 47.5% of 486 PIWH from South Africa felt shame as an internalized stigma (Santos et al., 2014). In addition, PIWH in Iran reported being

able to reveal their HIV status to their family, which was helpful for their family to accept their HIV status (Karamouzian et al., 2017). This means that these PIWH accepted their status and were comfortable to talk about HIV to their family. In the Netherlands, 262 PIWH reported that receiving sympathy and support (76.3%) and care avoidance (11.8%) were important to improving self-acceptance about their HIV status (Stutterheim et al., 2014).

Impact of HIV stigma. The impact of HIV stigma experience is associated with direct negative outcomes regarding the sense of both self and identity (Donnelly et al., 2016). Examples of negative outcomes are increased depression; increased negative coping; worsened health outcomes, working life, family life, and access to health services (Li et al., 2016; Logie et al., 2011; Santos et al., 2014; Stutterheim et al., 2014). Similarly, HIV stigma can also increase mental health problem, decrease treatment adherence, lower the access to health care services, increase problem related to employment (e.g., dismissal from work), lead to more housing-related issues (e.g., relocation), and heighten the risk for physical violence and/or verbal abuse (Smith & Santis, 2012). Karamouzian et al. (2017) also mentioned that negative outcomes can give rise to protective reactions such as self-isolation and concealing the HIV-positive status from health care providers, family members, and colleagues. Meanwhile, the experience of stigma also negatively impacts one's social network as a source of empowerment and support. So, if the PIWH loses his/her sources, he/she will get depressed, and it would lead to the PIWH having a low financial status in the social capital context (Cuca et al., 2017). Moreover, a qualitative study revealed some themes regarding the impact of stigma and discrimination among PIWH on ART,

namely fear, difficulty with identifying the location of health services, and non-adherence to ART (Mhode & Nyamhanga, 2016).

Measurement tools of HIV stigma. There are several tools to access stigma experience; however, only five tools are congruent with the objective of this study including: 1) Stigmatizing Attitudes Toward People Living with HIV (SAT-PLWH) (Beaulieu et al., 2014); 2) HIV Stigma Scale (Berger, Ferrans, & Lashley, 2001); 3) HIV Stigma Scale for Asian Living with HIV (ALWH) (Kamitani, Chen, Portillo, Tokumoto, & Rose, 2018); 4) 12-item short version of HIV Stigma Scale (Reinius et al., 2017), and 5) the 28-Item Internalized HIV Stigma Scale (Sayles et al., 2008).

1. Stigmatizing Attitudes Toward People Living with HIV (SAT-PLWH) was developed by Beaulieu et al. (2014), and it provides 42 items with 8 dimensions: occasional encounters (5 items), avoidance of personal contact (3 items), responsibility and blame (6 items), liberalism (4 items), non-discrimination (7 items), confidentiality of serological status (6 items), position on HIV/AIDS criminalization (6 items), and negative feelings (5 items). This tool uses a four-point Likert-type scale, from *strongly disagree* = 1 to *strongly agree* = 4. The Cronbach's alpha of this tool was .88 for the total scores, and its discriminant validity was proven valid.

2. HIV Stigma Scale developed by Berger, Ferrans, and Lashley (2001) provides 40 items covering the experiences, feelings, and opinions of PIWH since diagnosis with 4 subscales: personalized stigma (18 items), disclosure concerns (10 items), negative self-image (13 items), and concern with public attitudes (20 items). This tool uses a Likert-type scale consisting of four points, from *strongly disagree* = 1 to *strongly agree* = 4. Responses are summed to generate a total score (possible range = 40–160). The higher score refers to a higher stigma level. The overall Cronbach's

alpha coefficient of this tool is .96, and the validity for each subscale is good: .53 to .73 for personalized stigma; .52 to .75 for disclosure concerns; and $\geq .50$ for negative self-image and concern with public attitudes.

3. HIV Stigma Scale for Asian Living with HIV (ALWH) developed by Kamitani, Chen, Portillo, Tokumoto, and Rose (2018) provides 13 items with 4 subscales: personalized stigma (5 items), disclosure concerns (7 items), negative self-image (3 items), and concern with public attitudes (3 items). This tool uses a four-point Likert-type scale, from *strongly disagree* = 1 to *strongly agree* = 4. Here, the responses are summed to generate a total score (possible range = 13–52). A higher score refers to a higher stigma level. The overall Cronbach's alpha coefficient of this tool was calculated at .92, and its construct validity was good; the range for 10 items was .70 to .86. This tool has 13 items with an additional 3 items specific for an Asian culture.

4. The 12-item short version of the HIV Stigma Scale was developed by Reinius et al. (2017), and it was derived from the HIV Stigma Scale by Berger, Ferrans, and Lashley (2001). The short version provides 12 items with 4 subscales: personalized stigma (3 items), disclosure concerns (3 items), negative self-image (3 items), and concern with public attitudes (3 items). This tool also uses a four-point Likert scale, from *strongly disagree* = 1 to *strongly agree* = 4. Responses are summed to generate a total score (possible range = 12–48). A higher score refers to a higher stigma level. The Cronbach's alpha of this tool was determined to be good with a range of .80 to .88; likewise, validity was found to be good, having a range of .62 to .84.

5. Sayles et al. (2008) developed the 28-Item Internalized HIV Stigma Scale with 4 subscales: stereotypes (12 items), disclosure concerns (5 items), social relationships (7 items), and self-acceptance (4 items). This tool uses a five-point Likert scale, from *none of the time* = 0 to *all of the time* = 4. Responses are summed to generate a total score (possible range = 0–100). A higher score refers to a higher stigma level. It was tested in 202 PIWH in five communities and two HIV clinics in the United States. The internal consistency reliability of this instrument was determined at .93; the values for stereotypes, disclosure concerns, social relationships, and self-acceptance were .91, .85, .89, and .66, respectively. In addition, the content validity assessment was done through focus groups and cognitive interview stages, whereas the construct validity test examined the correlation between total score of the 28-Item Internalized HIV Stigma Scale and shame ($r = .58$), social support ($r = -.43$), mental health ($r = -.50$), and physical health ($r = -.14$).

After considering the tools of HIV stigma detailed above, the one developed by Sayles et al. (2008) is the most appropriate for this study due to its validity and reliability result; it consists of 28 items, which makes it less time consuming to fill than another one comprising 40 items or more as well as consistent with the conceptual framework and objective of this study.

Stigma Management Strategies Used by Persons Infected With HIV

Concept of stigma management. Stigma management reflects the effort or ability to control or reduce the stigma. The concept of stigma management derived from the Symptom Management Model (SMM) by Dodd et al. (2001) was adopted in this study. Virtually, according to Dodd et al (2001), there are three dimensions of

SMM: symptom experience, symptom management strategies, and symptom status outcomes. However, a part of SMM concerns itself with the support of the concept of stigma management strategies, which are symptom management strategies. Symptom management is a dynamic process that often changes over time or in response to the acceptance, or the lack thereof, of planned strategies. The components of symptom management focus on the specification of what (the nature of strategy), when, where, why, how much (intervention dose), to whom (recipient of intervention), and how (mode of delivery). As SMM deals with symptom management strategies, it can be reflected in stigma management strategies as a dynamic process in response to accepting oneself as a PIWH.

Current evidence of stigma management by persons infected with HIV.

Many researchers have studied stigma management; however, those studies have focused on the professional perspectives regarding the management of stigmas—e.g., studies about community-based interventions being beneficial for the enhancement of stigma-related knowledge and the reduction of stigma among PIWH in the community (Chidrawi, Greeff, Temane, & Doak, 2016; Frye et al., 2017; Pretorius, Greeff, Freeks, & Kruger, 2016). Nevertheless, few studies have explored the stigma management strategies employed by PIWH independently. Thapa et al. (2017) revealed that PIWH can manage the stigma they face through counseling with a professional health care provider and contact with members of the HIV community via peer groups. However, most PIWH try to conceal their HIV status and not all of them want or have a chance to be a part of a local HIV community. Thus, studies on stigma management from the PIWH perspective are needed in order to shed light on

how PIWH manage the HIV stigma independently and still keep their HIV status confidential as a right.

There are several strategies to manage stigma in such cases: share knowledge about HIV with others (Aryal, 2017; Rael et al., 2017); concealing the HIV status from others (Chenard, 2007; Daftary, 2012), preemptively and selectively disclose one's HIV status (Chenard, 2007; Mhode & Nyamhanga, 2016; Rael et al., 2017); maintain good emotional health and cope with stress (Aryal, 2017; Chenard, 2007); engage in spiritual practices (Mhode & Nyamhanga, 2016), share one's experience with a group (Aryal, 2017; Mhode & Nyamhanga, 2016); and seek support from others (Chenard, 2007; Rael et al., 2017).

Share knowledge about HIV. PIWH are stigmatized by people who do not have enough knowledge about HIV, especially about HIV transmission. Sharing knowledge about HIV transmission with people PIWH are in contact with can prevent misconceptions about HIV (Rael et al., 2017). Aryal (2017) found that increasing the knowledge about HIV can also decrease self-stigma and enhance the sense of responsibility for one's life. Moreover, a study by Rael et al. (2017) revealed that educating the family about HIV transmission, e.g., sharing the right information about HIV with the family members, can reduce stigma perceived by PIWH.

Hiding HIV status. This strategy is commonly used by PIWH due to the stigmatization they face from the public. Hiding one's HIV-positive status is a way to keep a secret from others and strive for normalcy (Chenard, 2007). Another study by Daftary (2012) revealed that social stigmatization affects the PIWH's choice regarding remaining silent about their HIV status, i.e., either not discussing the matter straightforwardly in public or negotiating to disclose their HIV status. Not only is this

true in regard to the public, concealing one's HIV status is present in the family context also. PIWH do not want to be prejudiced by a family member, which may lead them to feeling guilty, shamed, and helpless (Daftary, 2012).

Preemptively and selectively disclose one's HIV status. The preemptive and selective disclosure is a strategy to reveal one's HIV status to one's close people firstly. The trustworthiness of someone or the ability to confide in people one considers close to him/her plays an important role in the disclosure of HIV one's status. These strategies aim to anticipate negative social outcomes such as gossiping or rejection from friends and family (Rael et al., 2017). In a qualitative study by Rael et al. (2017), the participant reported that having preemptively and selectively disclosed their HIV status only those they considered close to them. Several previous studies have also revealed that the preemptive disclosure of one's HIV status was done in the scope of a family member, friends, work colleagues, neighbors, and volunteers (Chenard, 2007; Mhode & Nyamhanga, 2016; Rael et al., 2017).

Maintain physical and emotional health. Looking healthy in front of others is one strategy to manage the HIV stigma; this entails preventing people around PIWH from noticing their HIV status. A study from Nepal reported the management of stigma through showing the HIV-infected individual's physical ability and skill to work with others (Aryal, 2017). Besides physical well-being, PIWH strive to maintain stable emotional health as well. A study from the United States revealed that maintaining emotional health through coping with stress is one strategy HIV-positive people employ to strive for normalcy (Chenard, 2007).

Engage in spiritual practices. This is another strategy for managing stigma among PIWH. Yu, Chiu, and Ko (2018) revealed that HIV stigma affects spiritual

health among PIWH. For some, spiritual devotion connotes faith in God, which can serve as a way to build a strong coping strategy (Mhode & Nyamhanga, 2016).

Another study revealed that spiritual well-being has a negative correlation with stigma, especially personalized stigma and negative self-image (Hutson, Darlington, Hall, Heidel, & Gaskins, 2018). In some case, spirituality can provide a healing process for self-stigma or lead one to believe that everything that happens in one's life is God's will as illustrated by this statement, "I believe that if I die, it is God's will and not a result of AIDS" (Mhode & Nyamhanga, 2016).

Share one's experience with a friend or group. This strategy to manage one's stigma experience involves the sharing of one's experience with friends or in a group setting. Sharing one's HIV experience with others can decrease the level of stigma, strengthen relationships with others, and can improve one's knowledge about HIV, especially the need to take medicines for good health and in order to prolong life (Aryal, 2017). In another study from Tanzania, PIWH reported having experienced verbal stigma, social stigma, and perceived stigma. One strategy they employed to deal with their stigma experience as sharing their experience in the context of a support group (Mhode & Nyamhanga, 2016).

Seek support from others. Seeking the support of others is another strategy to manage HIV stigma. Support systems are usually derived from family members, friends, one's social circle, spouse, or health care provider. Support from family, friends, and the society is a very significant way for PIWH to with cope stigma. This statement illustrates this well, "Everybody treats me well. They love me a lot" (Rael et al., 2017). Another study from the United States revealed that social support can also come from friends and volunteers involved in issues related to HIV (Chenard,

2007). Furthermore, seeking the support of the HIV community is also effective in reducing stigma (Prinshloo & Greeff, 2015). In addition, one's partner or spouse can also be a source of social support for PIWH, which can assist them to manage their stigma experience (Rael et al., 2017). Moreover, Stutterheim et al. (2014) found that support from health care providers can help make the PIWH's experience a positive one by providing equal treatment, respect, and maintaining the confidentiality of their disease and treatment.

Factor related to stigma experience and management among persons infected with HIV. There are some factors related to experience of stigma experience and its management among PIWH. All factors in this review focus on demographics factors such as one's age, gender, sexual orientation, race/ethnicity, level of education, employment status, duration of HIV diagnosis, place of residence, social support, and religion.

Age. Age affects the way a person experiences stigma. Older people might have more experience related to stigma and stigma management than younger people. According to Cuca et al. (2017), older women have a significantly more positive perceived experience of HIV stigma than younger women do. A study by Caliarì, Teles, Reis, and Gir (2017) reported that, among people in aged 40 to 49 years, previous hospitalization experience was a better positive predictor for stigmatization, e.g., personal stigma and negative self-image, than it was among those of a younger age. In addition, a study by Ajong et al. (2018) revealed that after controlling for age was significantly associated with a high level of HIV stigma in Cameroon.

Gender. Gender, too, is associated with stigma experience and management. The life experience of stigma between men and women is different. Based on the

socio-cultural context in China, females reported significantly higher level of perceived internalized stigma than males (Li, Lin, & Ji, 2017). In contrast, a study from India reported significantly higher mean scores level for internalized stigma among men than women, whereas women reported significantly higher levels of enacted stigma than men (Malave, Ramakrishna, Heylen, Bharat, & Ekstrand, 2014).

Sexual orientation. Sexual orientation affects stigma experience and management; homosexuals, in particular, receive twice as much stigma in the social context as heterosexuals do (Mawar, 2005). A study from Italy reported that stigmatization through homophobia among heterosexual men was higher than that of heterosexual women toward both gay HIV-positive and gay HIV-negative persons. Moreover, both heterosexual men and women exhibited higher levels of homophobic attitudes (e.g., physical, social, emotional, affective) toward gay HIV-positive than gay HIV-negative individuals (Pala, Villano, & Clinton, 2017). Nevertheless, stigma affects, both heterosexual and homosexual PIWH, yet homosexuals received experience more discriminatory actions such as internalized stigma that is associated with the beliefs of a community regarding personal responsibility (Valles, Molina, & Dirkes, 2013).

Race/ethnicity. Race and ethnicity also influence HIV stigma. According to Lemin, Rahman, and Pangarah (2018), ethnicity (e.g., Iban, Malay, Bidayuh) was found to be an important predictor of HIV stigma regarding disclosure concerns in Malaysia. In addition, a study among women living with HIV reported that Asians/Pacific Islanders, African Americans, Hispanics, and Native Americans had a higher potential to experience stigma than Caucasians (Cuca et al., 2017).

Level of education. In addition, the level of educational attainment can affect one's response to stigma. The study by Ajong et al. (2018) reported an association between education above the secondary level and HIV stigma, wherein individuals with at least a tertiary level of education are less prone to being victims of stigma compared to their counterparts with a lower level of education. Incongruent with Ajong et al. (2018), a higher level of education (e.g., graduate-level education) has been linked to a higher level of understanding regarding HIV/AIDS and a lower level of stigmatization compared with the high-school level of education, which was associated with 60% greater odds of stigmatization (Coleman, Tate, Gaddist, & White, 2016).

Employment status. Employment status affects stigma experience among PIWH. PIWH who have an occupation might experience stigma in the workplace. A significant association between occupation and HIV stigma has been shown (Ajong et al., 2018). Another study reported that employment status, either self-employment or unemployment, a significant contributor to HIV stigma, wherein workplace being the source led to an increased level of perceived stigma (Pourmarzi, Khoramirad, & Gaeeni, 2017). PIWH preferred to be self-employed rather than an employee due to receiving a lower level of stigma (Pourmarzi, Khoramirad, & Gaeeni, 2017).

Duration of HIV diagnosis. Duration of HIV diagnosis is another factor that affects stigma among PIWH. Both stigma experience and stigma management are different between PIWH with a longer diagnosis of HIV and people that are newly diagnosed. In one study, PIWH who had been diagnosed with HIV for less than 5 years reported experiencing a higher level of stigma compared with PIWH who had been diagnosed for more than 5 years (Ajong et al., 2018). An explanation for this

could be that HIV stigma might be accepted more by PIWH diagnosed for more than 5 years than those for less than 5 years. However, PIWH for less than 5 years can receive help via counseling and emotional support in order to gradually accept their HIV status (Ajong et al., 2018).

Place of residence. Place of residence, either living in a rural or urban area, is a factor associated with stigma among PIWH. There is a different stigma level between living in rural and urban areas. Pourmarzi, Khoramirad, and Gaeeni (2017) revealed that living in a rural area is associated with a higher potential for receiving HIV stigma. Similarly, PIWH who live in a rural area experience a higher level of HIV stigma experience compared with PIWH who living in an urban area (Tzemis et al., 2013). On the other hand, the stigma experienced by PIWH in urban areas of India, who access HIV health care services, might increase due to the high level of stigma among health care providers towards PIWH (Ekstrand, Ramakrishna, Bharat, & Heylen, 2013).

Social support. Social support plays a role in stigma experience and management as well. According to Rueda et al. (2016), a moderate correlation between HIV stigma and lower social support exists. Social support includes support from family, friends, and the community. It can enhance the ability to manage stigma through social networking for both PIWH and caregivers (Hao & Liu, 2015). In addition, poor support from the family regarding one's HIV-positive status increases the level of perceived stigma significantly (Pourmarzi, Khoramirad, & Gaeeni, 2017). Moreover, receiving social support from the HIV community has been shown to reduce the HIV stigma experience in South Africa (Prinshloo & Greeff, 2015).

Religion. Religion has a significant impact on the level of stigma, which might be related to religious teaching. Religion, as a factor that causes stigma, has been reported to associate with a high level of stigma (Ajong et al., 2018). According to Srithanaviboonchai et al. (2017), there is a meaningful relationship between religion and anticipated stigma as well as religion and perceived stigma. According to the study Coleman, Tate, Gaddist, and White (2016), religiosity is not associated with decreasing the level of HIV stigma. On the other hand, religion can contribute to helping those concerned to accept themselves as PIWH (Tang & Chen, 2018).

HIV Situation and Care in Bali, Indonesia

HIV epidemic and national programs in Indonesia. The number of HIV cases in Indonesia is still high. Since 1987 when the first case of HIV was reported in Bali, Indonesia, HIV has spread to 407 of the 507 regencies/cities in Indonesia, with data from January to March 2017 reporting that the total number of HIV infections was 10,376 people; the highest percentage involved the 25-49 age group (69.6%); the ratio of men compared to women was 2:1; and the highest risk factor for HIV infection was MSM (28%) (Directorate General of Disease Control and Environmental Health, 2017). In Bali, the 1987-2016 data from Denpasar AIDS Commission (2016) reported the risk for infection was the highest among the heterosexual population (77.7%), of the 20-29 age group (38%), and residing in the regency/city of Denpasar (39%). Meanwhile, the total cumulative incidence of HIV/AIDS in Bali is 15,839 people, and the mortality due to HIV/AIDS as an overall rate of 10% per year (Utami et al., 2017). To prevent new cases of HIV/AIDS in Indonesia, the government has created regulations and health service programs.

The Indonesian government, through the Ministry of Health, provides health services programs for HIV persons in Indonesia such as Voluntary Counseling and Testing (VCT); Care, Support, and Treatment (CST) Program for those on ART; Methadone Therapy Program for injecting drug users (IDU); Sexually Transmitted Infections (STI) Program; and Prevention of Mother-to-Child Transmission Program (Directorate General of Disease Control and Environmental Health, 2017). These health programs are implemented to achieve the goals regarding HIV/AIDS management set by the government of Indonesia. The target of 55% of HIV/AIDS cases treated well by 2019 is in place; wherein this is an increase from the 42% baseline data percentage reported in 2014 (Ministry of Health, 2015).

The social response to persons infected with HIV. The social response to PIWH is related to their deviation from the norms and values of the society. For example, social responsibility regarding sexuality is considered a taboo issue and impolite for public discussion in Indonesia (Pakasi & Kartikawati, 2013). Sexuality is always associated with free sex or HIV/AIDS, so Indonesians typically label PIWH as persons that engage in bad sexual behavior. Moreover, social response is influenced by religion due to most Indonesians claim to have a certain religious faith. Islam, the majority religion in Indonesia, prohibits homosexuality, same-sex marriage, extramarital sex, and drugs use (Waluyo, Culbert, Levy, & Norr, 2015). This is reflected in the social values, norms, and attitudes toward such issues. In addition, a study showed that the society tends to respond poorly to the HIV gay or HIV MSM groups due to their inappropriateness in regards to the society's norms concerning same-sex relationships and the perception that such behavior or lifestyle can contribute to the HIV in Indonesia (Nugroho, et al., 2018).

Another influence on the social response towards HIV infection is derived from the traditional sociocultural norms and values of a given people and/or locally. For example, in Bali, set the role of the *Menyama Braya* concept is very significant. *Menyama Braya* (*nyama* means brothers or friends and *braya* means relatives of human beings) refers to the Balinese local wisdom of mutual cooperation of a human with another human (Sitiari, Suprapti, Sintaasih, & Sudibya, 2016; Suwitha, 2016). In other words, *menyama braya* is a guideline for the social interaction among their Balinese in daily life (Agung, Kanto, Wisadirana, & Ruja, 2017). However, the system of *menyama braya* might cause psychological burden among PIWH due to the traditional requirement that they participate actively in social life and maintain frequent and personal social contact with their peers; the avoidance of this duty, can lead to social repercussion. This poses obvious difficulties for PIWH, who try to keep their HIV status secret and pretend to look normal, i.e., like people without HIV, in social life.

Furthermore, the Balinese, who are predominantly Hindu, believe in *Karma*. The concept of *Karma* influences social response toward PIWH. *Karma* means that if someone does good things, they will receive good things, whereas if someone does bad things, bad will befall them as consequence (Chakraborty, 2014). Chakraborty (2014) also mentioned that *Karma* is not only about the action itself, but it also results in an action. A similar principle as that of *Karma* is found in Islam. The Quran 99:7 states, “So, whoever does any good act (even) to the weight of a particle will see it” (i.e., he/she will receive it or it will be returned to him/her). This concept is used as an exhortation to always do good *Karma* to other people.

Meanwhile, the government is directly involved in dealing with the population groups in Indonesia that are at a high risk of HIV transmission homosexuals, IDUs, and sex workers. The government enforces punishment on such groups based on the established policies and laws of the country concerning the groups or communities that deviate from the norms or values of the Indonesian society in respect to morality. The article 296 and 506 of the Criminal Code of Indonesia prohibit prostitution (Permata, 2014). Practice of homosexuality and extra-marital sex are also illegal, and punishable in Indonesia, e.g., Aceh Province. Although prostitution is illegal in almost all provinces in Indonesia, the Ministry of Health's regulation number 21/2013 about HIV prevention explicates that sex workers, as one of the key population groups involved in HIV transmission, should have equal rights to access HIV-prevention services (Permata, 2014).

Based on this situation, both the pervasive social response and the role of the government in dealing with population groups facing elevated risks for HIV infection, the existence of PIWH will always be associated with discriminatory stereotypes and labels. This sort of treatment will further increase the stigma toward PIWH.

Current evidence of HIV stigma in Indonesia. Stigma is one of the socio-cultural barriers to access HIV health services in Asian developing countries like Indonesia (Wasti et al., 2012). The phenomenon of HIV stigma in Indonesia is pervasive (Merati, Supriyadi, & Yuliana, 2005; Mutahar, Najmah, & Yenni, 2011). However, research about HIV stigma in Indonesia is rare; only 22 out of 5,984 HIV stigma studies were conducted in Indonesia among 125 countries in the world (Tran et al., 2019). HIV stigma in Indonesia comes from the community, family, health care

providers, and PIWH themselves. This section will describe the current situation of HIV stigma in Indonesia from the community level to the individual level.

In Indonesian communities, HIV stigma is a complex matter, not only as a result of the cultural identities of a given community, but also due to the role of religion, which can inadvertently contribute to the increase of the level of stigma (Waluyo, Culbert, Levy, & Norr, 2015). Due to the majority of Indonesians ascribing to a religious faith wherein prohibit extra-marital, same-sex marriage, and use of drugs is prohibited, stigma and discriminatory attitudes against the members of the high-risk populations of HIV transmission in Indonesia, such as sex workers, IDUs, MSM, are commonplace (Waluyo, Culbert, Levy, & Norr, 2015). In addition, it has been found that 58.3% of Indonesians exhibit behavioral discrimination or negative attitudes toward PIWH; for example, they refrain from buying vegetables from a vendor who is known to be HIV-positive (Mutahar, Najmah, & Yenni, 2011). Another reason for the negative attitudes Indonesians have toward PIWH may be their lack of knowledge about HIV/AIDS. According to the Indonesia Demographic and Health Survey, only 11% of women aged 15-49 years have a satisfactory level of knowledge about HIV/AIDS (Statistic Indonesia, 2012).

HIV stigma at the family level is also common in the Indonesian society. Nugroho et al. (2018) revealed the presence of stigma, discrimination, and low-level support from the family among HIV MSM in Indonesia. Another study also reported that gay men are afraid to explain their sexual orientation to their family, and they tend to conceal their sexual behavior (MSM) due to well-known vulnerability of MSM to HIV infection (Fauk, Merry, Sigilipoe, Putra, & Mwanri, 2017). According to Ismail (2015), women living with HIV suffer stigma and negative treatment from

their family members due to their apprehension about contracting HIV from them, misinformation or the lack of information about HIV/AIDS, and as a consequence of being married to an IDU husband. Often, the family's response is the ostracism of a family member due to that person's HIV infection. Nevertheless, according to Culbert et al. (2015), the family is the primary source of emotional support during and after incarceration among HIV prisoners in Indonesia. That study points out further that the family can also be the main source of social support, even when PIWH are concerned about disclosing their HIV status to family members preemptively.

Furthermore, stigma among health care providers toward PIWH is at a high level in Indonesia (Harapan et al., 2015; Waluyo, Culbert, Levy, & Norr, 2015). Value-driven stigma in the form of blaming and/or shaming the PIWH, refusing to share the same space with PIWH ($p < .001$), and overestimating the transmission of HIV from PIWH to them ($p < .001$) strongly correlated with the stigmatizing attitudes in Aceh, which has the lowest number of HIV cases in Indonesia. Similarly, Waluyo, Culbert, Levy, and Norr (2015) revealed that stigma among nurses in Indonesia is of a high level as well. Three significant contributors were identified—the nurse's religion, level of involvement in religion, and religion affiliation in the workplace. Moreover, a study conducted in Bali and Jakarta reported that health care providers treat HIV persons differently and even refuse care to them (Merati, Supriyadi, & Yuliana, 2005). This reflects that health care providers, especially at that time, were not mentally prepared to treat PIWH.

Yet, PIWH themselves can be the source of HIV stigma. Young Indonesians living with HIV, who have experienced of HIV stigma, report felt losing the desire to continue living (46%) and feeling worthless (Aggarwal et al., 2018). The same study

with preliminary design found that negative self-perception is more common among young Indonesians living with HIV than being afraid of contagion, verbal abuse, isolation from social life, stigma in the workplace, and neglect of health care. In addition, another study found that 33.3% of HIV prisoners experienced a high level of stigma due to factors like limited contact with the society and one's family, anticipated stigma, and being labeled an IDU apart from being a PIWH (Culbert et al., 2015). Similarly, Komalasari (2012) identified prisoners uninfected with HIV as the dominant group involved stigmatization of prisoners infected with HIV.

Summary of Literature Review

The concept of HIV stigma integrates the PIWH's experience of discreditation and stigmatization due to their deviation from a particular social norm. The HIV stigma experience comprises stereotypes, disclosure concerns, social relationships, and self-acceptance. The 28-Item Internalized HIV Stigma Scale is a valid tool and congruent with the conceptual framework of this study. Moreover, in order to describe the stigma management strategies, the questions focus on what, why, who, where, and how in regard to the management of stigma. In addition, there are some factors related to stigma experience and management among PIWH—age, gender, sexual orientation, race/ethnicity, level of education, employment status, duration of HIV diagnosis, place of residence, social support, and religion.

HIV cases in Indonesia remain high; the first case of HIV was reported in Bali in 1987. There are national programs to prevent HIV/AIDS in Indonesia; however, HIV stigma is still pervasive and a complex phenomenon to tackle in the Indonesian context. The social response to PIWH is function of the society's consideration that

HIV infection is a result of one's behaviors and/or lifestyle that deviate from social norms and values, which are informed by religion and cultural rules; consequently, this leads to HIV stigma. Although studies on HIV stigma in Indonesia have been conducted, they mostly focus on HIV stigma from the society and health care providers towards PIWH. Nevertheless, studies on HIV stigma based on the PIWH's perspective do exist, but they involve HIV prisoners, who might experience a different level of stigma from PIWH living in the community as it is easier for the latter to conceal their HIV status. Moreover, to author's knowledge, no study has as of yet explored stigma management strategies in Indonesia, which are essential for the development of interventions to decrease the level of stigma afflicting PIWH. Therefore, a study investigating simultaneously the experience and management of stigma among PIWH in Bali, Indonesia is both important and needed.

Chapter 3

Research Methodology

This chapter presents the details of the research methodology, which consists of the research design, study setting, samples size and respondents, sampling technique, instrumentation, translation of the instruments, validity and reliability of the instruments, data collection procedures, and data analysis. This chapter also discusses the ethics of pertaining to the research.

Research Design

A descriptive cross-sectional study was conducted to describe both the HIV stigma experience and stigma management strategies among PIWH in Bali, Indonesia.

Study Setting

There are hospitals, public health centers, and private clinics, which provide HIV services in Bali, Indonesia. However, four locations were selected due to providing free registered access for PIWH to receive ART regularly on monthly bases. They were two hospitals in Denpasar, one hospital in Badung, and one private clinic.

Sample Size and Respondents

The target population in this study was PIWH in Bali, Indonesia. PIWH in Bali frequent either the HIV Outpatient Department (OPD) of hospitals or private clinics. The total HIV cases in Bali in 2016 were 1,539 cases (Denpasar AIDS

Commission, 2016). According to Bartlett, Kotrlik, and Higgins (2001), the sample size for a descriptive study is based on this formula:

$$n_0 = \frac{(t)^2 * (s)^2}{(d)^2}$$

Note. n_0 = sample size; t = normal deviation for a two-tailed alternative at the level of significance (e.g., 5% = 1.96; 1% = 2.58); s = estimated standard deviation; d = margin of error for mean (point of scale * margin of error).

Therefore, the minimum sample size for this study was determined to comprise 194 respondents (Appendix J). However, taking into consideration the non-response rate (10%), the total sample size of this study was established at 215.

Sampling Technique

Respondents were recruited using purposive sampling. The following inclusion criteria were used to recruit respondents in this study: (1) adults aged 18 years or above, (2) aware of their HIV-positive diagnosis, (3) cooperative and communicative, (4) able to read and understand Bahasa Indonesia, and (5) willing to participate in this study as indicated by a signed informed consent. The exclusion criteria in this study were: (1) pregnant adults and (2) age of 65 years or above.

Instrumentation

The instruments used to measure the two variables of this study were the Demographic Characteristics Form for Persons Infected with HIV, the 28-Item Internalized HIV Stigma Scale, and Stigma Management Strategies Checklist (Appendix C, D, and G). Each instrument is described as follows:

Instruments

Part 1: Demographic Characteristics Form for Persons Infected With HIV (DCFPIWH). This was developed by the researcher based on literature review related to stigma experience and management. The DCFPIWH 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 living with (Appendix C).

Part 2: The 28-Item Internalized HIV Stigma Scale. Stigma experience was measured using the 28-Item Internalized HIV Stigma Scale developed by Sayles et al. (2008) (Appendix D). It consists of four subscales: stereotypes (12 items), disclosure concerns (5 items), social relationships (7 items), and self-acceptance (4 items). This tool uses a five-point Likert scale where *none of the time* = 0, *a little of the time* = 1, *some of the time* = 2, *most of the time* = 3, *all of the time* = 4. There were two negative items where the researcher had to reverse the score before analysis. To find the result of subscale scores, it was calculated by summing individual item scores and then dividing the sum by the number of items in that subscale (Culbert et al., 2015). Thus, to get the result of overall score, it was calculated by adding all subscale scores and dividing the sum by four in order to ensure that factors were weighted equally (Culbert et al., 2015). Moreover, the total score was transformed into a range of 0-100 based on the directions of the original tool (Sayles et al., 2008) (Appendix E). Higher scores refer to higher stigma levels. In addition, the interpretation of the level of HIV stigma experience was categorized into three levels—low, moderate, and high—for the total stigma as well as each subscale using the 33rd and 66th percentile cut-off values

from the distribution of scores (Gohain & Halliday, 2014). Therefore, the level of HIV stigma experience of this study was categorized as follows:

Table 1

Level of Total HIV Stigma and Each Subscale

Level	Mean score				
	Stereotypes	Disclosure concerns	Social relationships	Self-acceptance	Total stigma
Low	0.00-22.91	0.00-29.99	0.00-3.56	12.50-62.49	7.81-33.04
Moderate	22.92-43.75	30.00-65.00	3.57-21.43	62.50-87.50	33.05-51.56
High	43.76-93.75	65.01-100.00	21.44-71.43	87.51-100.00	51.57-87.13

Part 3: Stigma Management Strategies Checklist (SMSC). The SMSC was developed by the researcher based on the Stigma Management Strategies Open Questions (SMSOQ) (Appendix F). SMSC consists of eight parts based on Dodd's SMM (Appendix G). The first part provided the list of stigma management strategies used by PIWH. In addition, respondents were asked about the reasons for managing stigma; the information sources utilized to manage stigma; and people who helped in managing stigma. Moreover, they were queried about their satisfaction with and the effectiveness of a stigma management strategy, which involved their rating from the most effective and the least effective. One respondent could choose more than one answer except for the part dealing with satisfaction and effectiveness. A higher frequency or percentage refers to a larger number of stigma management strategies used by the respondent to prevent or reduce stigma.

Translation of instruments. The 28-Item Internalized HIV Stigma Scale was translated from English to Bahasa Indonesia. The translation process followed the

protocol suggested by Brislin (as cited in Polit & Beck, 2012) which consists of three steps: 1) selecting and preparing translators based on the criteria of one serving as a translator; 2) undertaking an iterative process; and 3) testing the translated version.

At the first step, the researcher selected two bilingual translators and one bilingual reviewer with satisfactory understanding of both languages and with a nursing education background (Appendix H). The English version was translated into Bahasa Indonesia by the first bilingual translator from Community Nursing, Udayana University, Bali, Indonesia, and the back translation from Bahasa Indonesia to English was carried out by the second bilingual translator from Adult and Gerontological Nursing, Syiah Kuala University, Aceh, Indonesia. The second translator was blinded to the original English version and did not know the first translator.

During the second step, after translation into Bahasa Indonesia and back translation into English, both the original English version and the back-translated English version of the questionnaire were compared by a bilingual reviewer from the Institute of Health Science of Bali, Indonesia. The bilingual reviewer detected and clarified minor discrepancies and ensured the translated instrument was equivalent in meaning to the original version. Finally, the translated version was pre-tested in order to determine its reliability.

The validity of the instrument. The content validity of SMSOQ was assessed by three experts in HIV/AIDS care (Appendix I). One expert was from Adult and Gerontological Nursing Department, Faculty of Nursing, Prince of Songkla University, Thailand. The other two experts were HIV researchers from Indonesia who have researched stigma in Indonesia—one from the University of Indonesia, and the other one was a head nurse with expert clinical experience in taking care of

patients with HIV/AIDS from Sanglah Hospital, Bali. The experts assessed the content in order to determine whether the items on the questionnaire were accurate, appropriate, and apt at answering the research question and achieve the objective of the study. The scale content validity index (S-CVI) is valid if the score is found to be 1.00 (Polit & Beck, 2006). However, an average S-CVI score of 0.90 is indicative of strong validity (Polit & Beck, 2012). In this study, the total CVI value of SMSOQ was 1.00.

Reliability of the instrument. The Indonesian version of the 28-Item Internalized HIV Stigma Scale was tested for internal consistency using the Cronbach's alpha coefficient. An acceptable r value of above .70 is required and perceived as acceptable (Polit & Beck, 2017). According to Radhakrishna (2007), a pretest of the instrument can be determined from a minimum of 20 samples that have the same characteristics as the research samples. Therefore, a reliability test was done among 20 selected respondents in this study, and the ensuring Cronbach's alpha coefficient was .92 (Appendix D).

Ethical Considerations

This study is in compliance with the ethical considerations and ethical principles involved in nursing research. According to Polit & Beck (2017), the ethical principles of nursing involve the beneficence of the research in relation to its subjects as well as their right to freedom from harm and discomfort, protection from exploitation, respect for human dignity, self-determination, full disclosure on the part of the researchers, and justice. This study concerned the right to full disclosure, justice, self-determination, comfort, and respect for human dignity. In addition,

permission for data collection in this study was obtained from two institutions, namely the Human Research Ethics Center for Social and Behavioral Sciences Institutional Review Board (IRB) Prince of Songkla University, Thailand (research code: PSU IRB 2019-NSt 005) and the Research Ethics Committee Faculty of Medicine, Udayana University/Sanglah Hospital Denpasar, Bali (research number 420/UN.14.2.2.VII.14/LP/2019) (Appendix L). However, there was protocol amendment during the process of this study, which was approved from the same institution: IRB Prince of Songkla University, Thailand (document number: PSU 606.1/322) and the Research Ethics Committee Faculty of Medicine, Udayana University/Sanglah Hospital Denpasar, Bali (document number 2371/UN.14.2.2.VII.14/LP/2019). The protocol amendment was needed due to the researcher changed or revised some parts of the content in particular the tool, e.g., SMSOQ was modified to SMSC, and it was approved.

When conducting HIV research, ethical consideration is necessary. The principle of HIV research found in the Muthuswamy study (2005) is congruent with the basic principles from of the Belmont Report (1979); hence the core ethic principles for this type of research are the PIWH's autonomy of identity, beneficence and non-maleficence, and justice in participating in research and care (Hlongwa, 2016; Power et al., 2018). Their detailed explanations are as follows:

Autonomy. The researcher explained the procedures, purpose, benefits, and risks of the research to the respondents in detail. The researcher also informed the respondents that they are free to discontinue their participation at any time and without any explanation. In order to ensure the anonymity and confidentiality of the respondents, a signed pre-informed consent, an informed consent, and labeling using

numeric codes were employed. Moreover, all collected data will be kept for at least five years and then destroyed (Anderson, Braxton, Dunham, Imker, & Rimkus, 2016).

Beneficence and non-maleficence. According to the Canadian Association for HIV/AIDS Research (2008), if the respondent has a psychological problem while participating in the study, the researcher should respect the confidentiality of the respondent, take measure to avoid causing any harm by refraining from imposing the values of the researcher on the respondent, and seek the help of a professional psychologist to assist the participant deal with the problem. In this study, no respondent exhibited any symptoms of distress. During the study's preparatory stage, the researcher contacted and made relevant preparations with a doctor and nurses that in the event of the respondent suffering a crisis caused by distress during filling the questionnaires, a break from the process should be taken as necessary. In fact, no such crises or any other severe problem were observed regarding any of the respondents of this study.

Justice. Throughout this study, the researcher treated all respondents the same way irrespective of gender, sexual orientation, religion, and cultural background. Moreover, the researcher prepared a reward for all respondents—a small souvenir in the form of a key chain from Thailand—as a token of appreciation for the respondents spending their valuable time to participate in the research. The reward was the same for every respondent.

Data Collection Producers

Data collection was conducted from March to May 2019. The procedure started with the preparation phase, which was followed by the recruitment phase, and the data collection phase. The process for this study was as follows:

Preparation phase. The preparation phase involved seeking and obtaining ethical approval, preparing the permission letter, and conducting a reliability test. After receiving ethical approval from the IRBs in Thailand and Bali, the researcher asked sought permission, via a letter, from the provincial government of Bali, Indonesia before asking for the permission of each study setting (Appendix M). Furthermore, after receiving permission letters from each study setting, a reliability test was conducted for the 28-Item Internalized HIV Stigma Scale, which included a face-to-face interview using SMSOQ.

Recruitment phase. Firstly, the researcher met the head nurse of the HIV OPD in order to explain the purpose of the research and the inclusion/exclusion criteria. Then the researcher selected nurses at the HIV OPD clinic to inform them about the study and the data-collection process. The role of these nurses was to approach the PIWH who met the inclusion criteria. After that, they gave the pre-informed consent forms to potential respondents to sign when they expressed an interest in participating in the research. Finally, the nurse accompanied the respondent to meet the researcher in a private room or counseling room directly.

Data collection phase.

1. The respondent was given a brief explanation in a private room—one on one with the researcher—that included the objectives and procedures of the study as well as

the potential benefits the respondent would have by participating in the research.

After agreeing to participate, the respondent was asked to sign the informed consent.

2. The researcher asked the respondent to fill in the questionnaire independently. Some respondents did not want to read, so the researcher read the questions to them and assisted them to answer the questions.

3. After the respondent finished the questionnaires, the researcher checked the completion of the questionnaires. All questionnaires were answered in approximately 15-25 minutes.

4. The researcher thanked the respondents, head nurse, nurses, doctors, and other health care providers for their cooperation.

Data Analysis

Data management. After data collection, all data were entered, checked, cleaned, and then transferred into a data file. The researcher used double data entry to prevent errors in processing the entry of data. This method compares the two data sets with the aim of ensuring the accuracy of the data and checking for outliers in order to clean the data.

Analyzing data. To analyze the data, the author used statistical software congruent with the methods related to descriptive statistics in order to answer the research questions.

1. Data involving demographic characteristics were analyzed using frequencies, percentages, means (*M*), and standard deviation (*SD*). Age was presented as *M* and *SD*, and maximum and minimum.

2. The 28-Item Internalized HIV Stigma Scale was analyzed using frequencies, percentages, ranges, means (M), and standard deviation (SD). Regarding the first research question, related to the description of the level of stigma, the total score of stigma was determined via M (SD). In addition, M (SD) were also used to identify the level of stigma in each subscale. Moreover, M (SD) were used to rank items by level of stigma, i.e., low to high level of stigma. Specifically, items 26 and 27 required the correction of their scores through the reversal of the five-point Likert scale and the change of the meaning of scale values.

3. SMSC was analyzed via frequencies and percentages for each type of stigma management strategy. In relation to the second research question, concerning the description of stigma management strategies, the higher frequencies or percentages indicated a greater number of stigma management strategies used by the respondent.

Chapter 4

Results and Discussion

This descriptive study was designed to describe the level of HIV stigma experienced by as well as the stigma management strategies in Bali, Indonesia. Two hundred and fifteen PIWH were purposively selected. The respondents were obtained from hospitals and a private clinic. The results and their discussion are presented in three parts:

Part 1: Demographic characteristics of persons infected with HIV.

Part 2: Stigma experienced by persons infected with HIV.

Part 3: Stigma management strategies used by persons infected with HIV.

Results

Demographic characteristics of persons infected with HIV. Two hundred and fifteen PIWH completed three questionnaires. The demographic characteristics of the respondents are presented below (Table 2). More than half of them (50.2%) ranged in age from 19-35 years old ($M = 35.47, SD \pm 8.51$). Mostly males participated in this study (63.3%). Over half of the respondents identified their sexual orientation as heterosexual (74.5%), and the others were homosexual (15.3%) and bisexual (10.2%). In terms of religious affiliation, most of the respondents in this study were Hinduism (58.6%), Islam (25.6%), and Protestant Christianity (9.3%). Moreover, the two most common ethnicities were Balinese (63.3%) and Javanese (24.2%). Over half (52.6%) of the respondents had completed senior high school, and the employment status for more than half of them—both before HIV diagnosis (59.5%) and after HIV

diagnosis (52.1%)—was self-employed. One hundred and forty-five (67.4%) reported being diagnosed with HIV between the age of 19 and 35 years, and 65.6% reported having had the diagnosis for more than two years. One hundred and fifty-one respondents (70.2%) lived in an urban area while 29.8% of them lived in a rural area. More than half of the respondents (68.9%) reported that they lives with their family.

Table 2

Demographic Characteristics of PIWH (N = 215)

Demographic Characteristic	Frequency	Percentage
Age (years)		
($M = 35.47$; $SD \pm 8.51$; Min. = 19; Max. = 64)		
19-35	108	50.2
36-55	103	47.9
56-64	4	1.9
Gender		
Male	136	63.3
Female	79	36.7
Sexual orientation		
Heterosexual	160	74.5
Homosexual	33	15.3
Bisexual	22	10.2
Religion		
Hinduism	126	58.6
Islam	55	25.6
Protestant Christianity	20	9.3
Buddhism	8	3.7
Catholicism	4	1.9
Other	2	0.9

Note. M = Mean; SD = standard deviation; Min = Minimum; Max = Maximum

Table 2 (continued)

Demographic Characteristics of PIWH (N = 215)

Demographic Characteristic	Frequency	Percentage
Race/Ethnicity		
Balinese	136	63.3
Javanese	52	24.2
Betawi/Jakarta	2	0.9
Chinese	3	1.4
Others (e.g., people from Sumatra, Kalimantan, Sulawesi, Maluku, Nusa Tenggara Islands, etc.)	22	10.2
Level of education		
No education	1	0.5
Primary school	19	8.8
Junior high school	46	21.4
Senior high school	113	52.6
Undergraduate/Post-Graduate	36	16.7
Employment status before HIV diagnosis		
Unemployed	16	7.4
Employed		
Self-employed/business owner	37	17.2
Private-sector employee	128	59.5
Government employee	7	3.3
Others profession	27	12.6
Employment status after HIV diagnosis		
Unemployed	25	11.6
Employed		
Self-employed/business owner	49	22.8
Private-sector employee	112	52.1
Government employee	6	2.8
Other profession	23	10.7
Age at HIV diagnosis (years)		
≤ 18	4	1.9
19-35	145	67.4
36-50	59	27.4
51-64	7	3.3

Table 2 (continued)

Demographic Characteristics of PIWH (N = 215)

Demographic Characteristic	Frequency	Percentage
Duration since HIV diagnosis		
< 1 year	42	19.5
1-2 years	32	14.9
> 2 years	141	65.6
Place of residence		
Rural	64	29.8
Urban	151	70.2
People living with		
Alone	37	17.2
Family	148	68.9
Friend(s)	8	3.7
Spouse	22	10.2

Stigma experienced by persons infected with HIV. Overall, the mean score of total stigma was at a moderate level ($M = 42.88$, $SD \pm 17.59$); the subscale scores were at a moderate level as well. The data for each subscale were: stereotypes ($M = 34.91$, $SD \pm 21.89$), disclosure concerns ($M = 46.32$, $SD \pm 29.35$), social relationships ($M = 16.73$, $SD \pm 17.43$), and self-acceptance ($M = 73.57$, $SD \pm 20.34$) (Table 3).

Table 3

Range, Mean, Standard Deviation and Level of HIV Stigma Experience (N= 215)

Subscale	Range	<i>M</i>	<i>SD</i>	Level*
Stereotypes	0.00 – 93.75	34.91	21.89	Moderate
Disclosure concerns	0.00 – 100.00	46.32	29.35	Moderate
Social-relationships	0.00 – 71.43	16.73	17.43	Moderate
Self-acceptance	12.50 – 100.00	73.57	20.34	Moderate
Total Stigma	7.81 – 87.13	42.88	17.59	Moderate

Note. *M* = mean score; *SD* = standard deviation; * = the mean scores for a low, moderate, and high stigma level for each subscale and for total stigma were different. They were based on the 33rd and 66th percentile cut-off values of the distribution of scores for each subscale and total stigma. This was adapted from the paper entitled, “Internalized HIV-stigma, mental health, coping and perceived social support among people living with HIV/AIDS in Aizawl District: A pilot study,” by Z. Gohain and M. A. L. Halliday, 2014, *Psychology*, 5, 1794-1812.

The three highest and lowest mean scores of the 28-Item Internalized HIV

Stigma Scale. Additionally, Table 4 shows the three highest mean scores and the three lowest mean scores of the 28-Item Internalized HIV Stigma Scale rated by respondents. Feeling uncomfortable with telling others about their HIV status ($M = 85.50$, $SD \pm 24.25$); feeling uncomfortable with talking about HIV with family ($M = 81.75$, $SD \pm 27.00$); considering important to keep their HIV status a secret from co-workers ($M = 67.75$, $SD \pm 37.50$) were the items with the highest mean scores in the self-acceptance subscale. Oppositely, the three lowest mean scores were observed for feeling abandoned by their family due to their HIV status ($M = 13.50$, $SD \pm 25.00$), nurses and doctors treating PIWH as if they are contagious ($M = 9.75$, $SD \pm 18.75$), and nurses and doctors disliking providing care for PIWH ($M = 6.50$, $SD \pm 16.00$); these items were a part of the social-relationships subscale.

Table 4

Item Ranking: Three Highest Mean Scores and Three Lowest Mean Scores of the 28-Item Internalized HIV Stigma Scale (N = 215)

Ranking order	Item no.	Content of item	<i>M</i> ± <i>SD</i>	Subscale
1	26	Feeling uncomfortable with telling others about their HIV status	85.50 ± 24.25	Self-acceptance
2	27	Feeling uncomfortable with talking about HIV with family	81.75 ± 27.00	Self-acceptance
3	28	Considering important to keep HIV status a secret from co-workers	67.75 ± 37.50	Self-acceptance
...				
26	20	Feeling abandoned by family members due to HIV infection	13.50 ± 25.00	Social-relationships
27	18	Nurses and doctors treating PIWH as if they are contagious	9.75 ± 18.75	Social-relationships
28	19	Nurses and doctors disliking providing care for PIWH	6.50 ± 16.00	Social-relationships

Note. *M* = Mean; *SD* = standard deviation

Stigma management strategies used by persons infected with HIV. Thirty-seven stigma management strategies were found in this study. The three most often used strategies by PIWH were praying (70.7%), positive thinking (70.2%), and keeping HIV status a secret (66.0%). Meanwhile, the three least used strategies were forgiveness of oneself, relatives, and situations (12.6%), creating ulterior reasons (hiding the true reasons) to explain their health condition and/or illness (13.5%), and being selective when choosing friends or a community where to live or work (13.5%) (Table 5).

Table 5

Stigma Management Strategies Used by Persons Infected With HIV (N = 215)

Stigma management strategies	Frequency	Percentage
Praying	152	70.7
Positive thinking	151	70.2
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 PIWH	132	61.4
Working	127	59.1
Behaving like 'normal' people who do not have HIV	125	58.1
Hanging out or traveling	124	57.7
Pursuing a hobby (doing favorite daily activities)	114	53.0
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 health care providers	93	43.3
Hiding ARV drugs or changing their package labels	91	42.3
Seeking support from the family	83	38.6
Sleeping enough	82	38.1
Trying to do not care about what people say or do	74	34.4
Seeking support from the spouse	69	32.1
Abstain from 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
Seeking the support of a friend	49	22.8
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 book	44	20.5
Relocation—moving from one area to another	43	20.0
Seeking information from health care 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

Table 5 (continued)

Stigma Management Strategies Used by Persons Infected With HIV (N = 215)

Stigma management strategies	Frequency	Percentage
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 community where to live or work	29	13.5
Forgiveness (to oneself, relatives, and situation)	27	12.6

Reasons given by PIWH for managing the stigma. Several reasons for managing HIV stigma were discovered in this study. Most respondents answered that they managed stigma in order to either decrease stress or avoid it (68.8%); maintaining good health (44.7%) as the least frequent encountered reason (Table 6).

Table 6

Frequency and Percentage of Reasons for Managing Stigma (N = 215)

Reason for managing stigma	Frequency	Percentage
To decrease and/or avoid stress	148	68.8
To live like 'normal' people that do not have HIV	124	57.7
To transform negative thoughts to positive ones	119	55.3
To maintain good health	96	44.7

Source of information for managing stigma. Table 7 shows the frequency and percentage of information sources accessed by the respondents to manage HIV stigma. The reported sources of information were self-study, health care providers, friends, spouses, and family members. One hundred and forty-seven respondents

obtained information on how to manage stigma via self-study (68.4%), and forty-four (20.5%) others received such information from a friend.

Table 7

Frequency and Percentage of Information Sources Accessed by PIWH to Manage Stigma (N = 215)

Information source	Frequency	Percentage
Self-study (e.g., internet, TV, health promotion literature, socialization)	147	68.4
Health care providers (doctors, nurses, counselors)	111	51.6
Spouses	55	25.6
Family	50	23.3
Friends	44	20.5

People assisting in managing stigma. Table 8 shows the frequency and percentage of types of people the respondents identified to play a role in managing the HIV stigma they face. Most respondents helped themselves (66.0%) and seldom sought help from a friend (22.8%).

Table 8

Frequency and Percentage of Types of People Helping in Managing Stigma (N = 215)

People who helped manage stigma	Frequency	Percentage
Oneself (PIWH)	142	66.0
Health care providers (doctors, nurses, counselors)	93	43.3
Family	83	38.6
Spouses	69	32.1
Friends	49	22.8

Satisfaction with and effectiveness of stigma management strategies. More than half of the respondents (65.6%) reported being satisfied with their stigma management strategies, and the majority (96.3%) perceived having chosen effective stigma management strategies (Table 9).

Table 9

Frequency and Percentage of Satisfaction With and Effectiveness of Stigma Management Strategies Used by PIWH (N = 215)

Satisfaction with and effectiveness of stigma management strategies	Frequency	Percentage
Satisfied	141	65.6
Quite satisfied	66	30.7
Not satisfied	8	3.7
Effective	207	96.3
Ineffective	8	3.7

Most effective HIV stigma management strategies. The most effective stigma management strategies reported by the respondents of this study are shown in Table 10. Sixty-two (28.8%) of the respondents answered that the most effective stigma management strategy was praying or participating in spiritual practices.

Table 10

Frequency and Percentage of the Most Effective HIV Stigma Management Strategies
(*N* = 215)

Stigma management strategy	Frequency	Percentage
Praying or performing spiritual practices	62	28.8
Positive thinking	57	26.5
Working or finding another activity to occupy one with	34	15.8
Pursuing a hobby	21	9.8
Hanging out or traveling	15	7.0
Sharing their story with or seeking support from close friends	11	5.1
Sharing their story with or seeking support from family	11	5.1
Sharing their story with or seeking the support of the spouse	4	1.9

Least effective HIV stigma management strategies. Table 11 shows the first least effective stigma management strategies reported by the respondents of this study. One hundred and six (49.3%) of the respondents stated that all of the strategies they chose to follow were effective. However, the least effective stigma management strategy identified in this study was staying alone (21.9%).

Table 11

Frequency and Percentage of the Least Effective HIV Stigma Management Strategies Employed by PIWH to Deal with HIV Stigma (N = 215)

Stigma management strategy	Frequency	Percentage
No ineffective strategies were identified (all strategies were reported being effective to some extent)	106	49.3
Staying alone	47	21.9
Sharing their story with or seeking support from: friends, family, and spouse	36	16.7
Sleeping enough	14	6.5
Working	12	5.6

Discussion

The findings of this study provide the level of HIV stigma experience and the list of stigma management strategies among PIWH in Bali, Indonesia. This part presents the discussion of the findings based on the research questions and research objectives of this study. The discussion consists of the demographic characteristics of the respondents, stigma experienced by PIWH, and stigma management strategies used by PIWH.

Demographic characteristics of persons infected with HIV. These findings highlighted that 50.2% of the respondents' ages ranged from 18-35 years old which was in the young-adult phase and 63.3% was male. These findings were congruent with the national statistics of the Directorate General of Disease Control and Environmental Health, Ministry of Health, Republic of Indonesia (2018) in which adult ages in range from 25-49 years old were the highest percentage (69.2%) of

PIWH rather than other age groups and males infected with HIV (62%) were higher than females. In addition, 74.5% was heterosexual in this study wherein HIV/AIDS data in Bali reported that the total of heterosexuals with HIV (77.7%) more than both homosexuals (11.1%) and bisexuals (0.4%) (Denpasar AIDS Commission, 2016). According to Bello, Kabakama, Baisley, Francis, and Jones (2019), heterosexuals in lower and middle-income countries were associated with high-risk sexual behavior due to oral and anal sexual activity through inconsistent condom use and having sex with multiple partners. This could point out the high-risk of HIV transmission occurs among heterosexual males in the young-adult phase in a lower and middle-income country, e.g., Indonesia, which cause high number of HIV cases among heterosexual.

These findings also highlighted that ethnicity was Balinese (63.3%) due to this study having been conducted in Bali. Bali, as one of top ten provinces, has a high number of HIV infection cases (sixth position with 510 cases) and AIDS cases (fourth position with 244 cases) in Indonesia (Directorate General of Disease Control and Environmental Health, Ministry of Health, Republic of Indonesia, 2018). In addition, the most common religion in this study were Hindu (58.6%), which is congruent with a study by Kumar et al. (2017) in that 78.8% of PIWH were Hindu. Moreover, senior high school was the highest percentage (52.6%) among the level of education, which has a similar result with Januraga et al. (2018) and Utami et al. (2017) who conducted HIV research in Indonesia.

This study showed that private employee, both before (59.5%) and after (52.1%) HIV diagnosis, was the highest percentage for employment status. This finding was congruent with the national statistics of the Directorate General of Disease Control and Environmental Health, Ministry of Health, Republic of Indonesia

(2018) in which PIWH work as a private employee (1,187 cases during October to December 2017). In addition, 70.2% lived in an urban area and 68.9% were living with their family which were congruent with HIV/AIDS data in Bali. This could support that HIV transmission is mostly in an urban area and transmitted by those who live with their family. According to Denpasar AIDS Commission (2016), PIWH were mostly living in urban areas, such as Denpasar and Badung, wherein Denpasar has 39% and Badung has 16.1% of 1,539 PIWH in Bali.

Stigma experienced by persons infected with HIV. The level of stigma experience was at a moderate level ($M = 42.88$, $SD \pm 17.59$). The findings reflected that respondents perceived themselves as deviant from the cultural norm and possessed a ‘spoiled identity’ in their community. Furthermore, Sayles et al. (2008), highlighted that the intensity of stigma may be increased among the group who have been marginalized due to gender and ethnicity.

Over half of the respondents in this study were male, which corroborates with the previous result that males significantly internalized HIV stigma more than females in India (Malave, Ramakrishna, Heylen, Bharat, & Ekstrand, 2014). Stereotyping by society develops stigma for male due to two reasons. First, male had associated sex with multiple partners and inconsistent use condom (Carlos et al., 2017) that might result in a female being infected with HIV. Second, males being labeled as “masculine” which could also increase internalized stigma among males infected with HIV (Okoror, Falade, Walker, Oloruniana, & Anaele, 2016). Masculinity is one of the inequalities of traditional gender norms in the social process, and males infected with HIV experience internalized stigma because of failing to embody masculinity as manly and adequately to be self-reliant family providers. These males also experience

less power in the community due to their HIV status which is regarded as a fatal illness (Wyrod, 2011).

Furthermore, more than half of the respondents were Balinese and most of them followed Hinduism, in which they adhered to the philosophy of Hinduism. A part of Balinese culture and local wisdom is a mutual relationship between human and human or “*Menyama braya*” concept (Sitiari, Suprapti, Sintaasih, & Sudibya, 2016; Suwitha, 2016). PIWH may worry about meeting people and being fearful of the community in Bali guessing their HIV status by noticing the physically changes in them. This may due to knowledge about HIV/AIDS of society need to improve in Bali, Indonesia. According to the Indonesia Demographic and Health Survey (2012), there was only a small number of Indonesians who understand HIV/AIDS comprehensively. This may impact on the negative attitude of Indonesians toward PIWH (Mutahar, Najmah, & Yenni, 2011).

All the subscales were also at a moderate level. However, the self-acceptance subscale has the highest mean score among the other subscales. This reflects that the respondents had not yet accepted themselves as PIWH. They had a negative feeling; they felt shame, guilt, and miserable after being diagnosed with HIV (Donnelly et al., 2016; Karamouzian et al., 2017; Santos et al., 2014). Furthermore, three items under the self-acceptance subscale had the highest mean score. The three highest items were feeling uncomfortable with telling others about their HIV status ($M = 85.50, SD \pm 24.25$); feeling uncomfortable with talking about HIV with family ($M = 81.75, SD \pm 27.00$); and considering important to keep HIV a secret from co-workers ($M = 67.75, SD \pm 37.50$). The respondents in this study were not yet acceptable with their HIV status and in particular telling anyone including discussing it with their family or

telling their co-workers. This would appear to indicate that the respondents were apprehensive of people will knowing their HIV status, thus they isolated themselves from social life, which then would intensify the stigma. Consequently, the trajectory toward self-acceptance as PIWH will have difficulty to achieve (Albright & Fair, 2018).

The three lowest mean scores were under social relationships. This reflects that the lower level of stigma perceived by respondents from their family, nurses, and doctors based on three lowest mean scores, namely feel abandoned by family because have HIV ($M = 13.50, SD \pm 25.00$); nurses and doctors treat PIWH as if they are contagious ($M = 9.75, SD \pm 18.75$); nurses and doctors dislike caring for PIWH ($M = 6.50, SD \pm 16.00$). The findings from this study are inconsistent with previous studies that mentioned PIWH had avoidance and discrimination experiences from family activity, spouse, health care providers, society (Fazeli et al., 2017; Karamouzian et al., 2017; Mhode & Nyamhang, 2016; Santos et al., 2014; Stutterheim et al., 2014). It could nevertheless be argued that HIV health services in these study settings are isolated from other OPDs or clinics so that respondents can build comfortable interaction, communication, and relationship with health care providers.

Interestingly, the mean score of this finding is quite similar with previous result in India by Gohain and Halliday (2014) that found the overall stigma was at a moderate level ($M = 41.07, SD \pm 16.66$). In addition, a further supporting mean score ($M = 41, SD \pm 19$) comes from Sayles et al. (2009) who conducted a study in Los Angeles. Remarkably, the mean score of internalized HIV stigma in this study ($M = 42.88, SD \pm 17.59$) is quite similar with two others. This could point out that internalized HIV stigma is common phenomenon around the world. It supported a

previous study by Stuenkel and Wong (2013) stated that stigma is a worldwide phenomenon, e.g., character blemishes toward PIWH.

Stigma management strategies used by persons infected with HIV. Of the 37 strategies that were found in this study, praying was the most common and the first most effective used by PIWH to manage stigma. Most religions in Indonesia believe in the existence of God and the power of religiosity. Religion might lead respondents to worship God through prayer, so that they may feel calmer, peaceful, and sincere; feel guided and protected by God; accept themselves as PIWH to continue their life. As proposed by Tang and Chen (2018), religion teaching helped PIWH to experience peace of mind, accept their HIV status and their illness, be willing to access HIV health care services, and there was still a place in the church for them regardless of their health status. Beyond praying; reading the holy book, meditation or *Yoga*, and accepting whatever happens as the will of God were also an implementation of religiosity and spiritual activity. Previous findings revealed that spiritual well-being had a negative correlation with personalized stigma and self-image (Hutson, Darlington, Hall, Heidel, & Gaskins, 2018) and that HIV stigma affected spiritual health (Yu, Chiu, & Ko, 2018). This could point out that the implementation of religiosity and spiritual activity are common strategies used by most respondents to manage HIV stigma and achieve the purpose of spiritual health.

As well as praying, positive thinking was the second most common and effective stigma management strategy used by PIWH. This study also found that more than half of the respondents managed stigma due to wanting to transform negative thoughts to positive ones. These findings appear to be well substantiated by the previous study from India in that positive coping strategies had a positive impact on

health outcomes (Kumar, Mohanraj, Rao, Murray, & Manhart, 2015). Positive strategies can be developed to enhance problem-solving skills to improve adherence to treatment and decrease internalized HIV stigma among young adults in the United States (Mimiaga et al., 2019). This could point out that positive thinking is a strategy that could prevent worsening psychological distress as a consequence of perceived stigma among PIWH. This lends support to the previous finding that perceived stigma had a relationship to psychological well-being and prospectively predicted occurring psychological distress (Miller, et al., 2016).

Keeping HIV status a secret occupied the third-highest percentage as a strategy in managing HIV stigma. It might be the safest way to avoid any type of HIV stigma in particular from society. These findings corroborated the previous results by Arrey, Bilsen, Lacor, and Deschepper (2015), in that the reason PIWH 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 HIV status a secret was done through social withdrawal and self-isolation to cope with enacted stigma (Judgeo & Moalusi, 2014). This could point out that respondents may feel more comfortable to live life without anyone knowing about their HIV status. Similarly, this study found that the respondents have chosen sharing their story with or seeking support from friends, family, or spouse as the least effective strategy. This confirms findings from the previous study revealed that Sub-Saharan African women in Belgium keep their HIV status a secret to maintain their self-esteem, felt stronger, and to be confident (Arrey, Bilsen, Lacor, & Deschepper, 2015).

On the other hand, the lowest percentage for stigma management strategies was forgiveness either to oneself, relatives, or situation. Forgiveness is a path to

relieve feelings of guilt through a focus on forgiving the “who” which is central to forgiveness (Breitbart, 2018). Similarly, forgiveness is related to improving the physical health quality of life among adult PIWH (Martin, Vosvick, & Riggs, 2012). However, forgiveness in this study is the lowest stigma management strategy which may be due to the stigma level of self-acceptance which is the highest mean score compared to the other subscales, so that the respondents find it hard to forgive oneself, relatives, or situation. According to Chung (2016), self-compassion is a concept of being kind, understanding, and accepting of oneself; low self-compassion moderated the strong relationship between lack of forgiveness and depression. This could point out that the more a person cannot accept him-/herself as PIWH, the more difficult for the person to have forgiveness for oneself, situation, or condition.

Meanwhile, being selective in choosing friends or community was an infrequent strategy used by respondents to manage stigma. This study found only 3.7% of respondents living with a friend and one of the least effective stigma management strategies was sharing their story with or seeking support from friends. This may reflect that the respondents fear a break up in the relationship with friends or they did not trust to their friends and community where they live or work due to being afraid that many people will find out their HIV status. According to Rael et al. (2017), being selective in choosing friends or community was complex and related to HIV status disclosure due to PIWH must control how, when, and to who they choose to disclosure to, and whether friends or community have learned to correct information about HIV/AIDS. This can show that respondents prefer to keep a secret rather than share a problem or disclose their HIV status to friends or community. Moreover, being selective in choosing friends was supported through the lowest

percentage from a friend as people who help to manage the stigma and as an information source to manage stigma in this study.

Similarly, very seldom did respondents use the strategy of creating ulterior reasons (hiding the true reasons) to explain their health condition and/or illness. This might happen in cases where people or society notice or ask about the physical changes, then the respondents tried to answer with another reason about their health condition and/or illness to conceal their HIV status and prevent any stigma from society. Physical changes (e.g., loss weight), as one HIV symptom, occur due to decreased immune response, an increased progression of the disease (e.g., increase susceptibility to opportunistic infection), decreased functional capacity, and decreased adherence of treatment (Lee et al., 2009; Rote, 2012). A previous study on the association of stigma from society with the appearance of HIV symptoms supports previously elaborated statements (Earnshaw et al., 2015). This could point out that creating ulterior reason to explain their health condition and/or illness used by respondents as a stigma management strategy in case the public noticed the appearance of HIV symptoms, e.g., physical changes. Otherwise, they acted like normal people who do not have HIV as shown in more than half the respondents in this study. Congruent with the previous study from Nepal, PIWH showed the physical ability and skill to work like normal people in social life as a strategy to manage their stigma (Aryal, 2017). Moreover, over half of the respondents agreed that the reason for managing the stigma was to live like normal people who do not have a HIV status.

Furthermore, more than half the respondents managed the stigma due to wanting to decrease and/or avoid stress; to live like normal people that do not have HIV; to transform negative thoughts to positive thoughts. These findings are

congruent with the previous study in the United States by Chenard (2007) which revealed that managing stress is one strategy to strive for normalcy and maintain emotional health. Moreover, less than half stated that the reason in managing the stigma was to maintain good health. Maintaining good health through routine exercise among PIWH can significantly improve as well as prevent disease progression at any stage of HIV infection (Jagers & Hand, 2016). This supported the findings in this study in that more than half of the respondents manage the stigma through maintaining good health, such as adherence to treatment, to keep working, preoccupation with other things or activities, and to do hobbies.

This study found more than half of the respondents receive information to manage the stigma through self-study. The respondents also helped themselves to manage the stigma. It may be due to stigma being a social process to categorize people (Goffman, 1963) and some issues are associated with religious rules in Indonesia (Waluyo, Culbert, Levy, & Norr, 2015). Due to this situation and condition, the respondents tried independently through self-study to find information about stigma management (e.g., searching the internet, health promotions, watching TV) and by helping themselves. Moreover, family, friends, spouse, and health care providers were considered as social support, either as a source of information or people who can help to manage the stigma. Several previous studies revealed that social support has a benefit beyond decreasing the stigma, such as adhering to ARV treatment (Helms et al., 2017; Li, Murray, Suwanteerangkul, & Wiwatanadate, 2014; Rueda et al., 2016) and increasing the ability to manage stigma among PIWH (Hao & Liu, 2015).

The majority of the respondents (96.3%) agreed that stigma management used by them was effective and 65.6% was satisfied. Moreover, beyond the most effective,

there was a list of the least effective stigma management strategies, wherein the first least effective was staying alone. Staying alone might lead to recalling the past memory when PIWH realized they were diagnosed with HIV, and then negative thinking and feelings come in their mind. This is in line with the previous study which revealed people who have psychological distress will suffer from psycho-emotional problems, and perceived negative influences from people (family, friends, or spouse) due to the feeling of loneliness (Miller et al., 2016; Peltzer, Ogawa, Tusher, Farnan, & Gerkovich, 2017).

Chapter 5

Conclusion and Recommendations

The summary of the study findings in the conclusion, strengths and limitations, challenges and lesson learned of the study are presented in this chapter. Furthermore, the recommendations including the implication of this study for nursing practice, nursing education, and nursing research are also suggested in this chapter.

Conclusion

The objectives of this study were to describe the level of HIV stigma experience and stigma management strategies among PIWH in Bali, Indonesia. The conceptual framework of stigma experience was derived from Sayles et al. (2008). In addition, the Symptom Management Model by Dodd et al. (2001) was used for HIV stigma management strategies. A descriptive cross-sectional study was conducted to collect 215 PIWH in four locations in Bali, Indonesia. The Demographic Characteristics Form for Persons Infected With HIV (DCFPIWH), the 28-Item Internalized HIV Stigma Scale, and Stigma Management Strategies Checklist (SMSC) were used to gather the data about HIV stigma experience and management strategies. Three experts assessed the DCFPIWH and SMSOQ. The 28-Item Internalized HIV Stigma Scale was undertaken by three bilingual experts for back-translation. The internal consistency (Cronbach's alpha) of the Indonesian version of the 28-Item Internalized HIV Stigma Scale was .92. Descriptive statistics were used for data analysis.

The findings of this study showed that the overall mean score of HIV stigma experience was at a moderate level ($M = 42.88$, $SD \pm 17.59$). The highest mean score from the content of the items was in the self-acceptance subscale ($M = 85.50$, $SD \pm 24.25$) and the lowest was in the social-relationships subscale ($M = 6.50$, $SD \pm 16.00$). In addition, among 37 stigma management strategies most often used by PIWH, the three highest percentages were praying (70.7%), positive thinking (70.2%), and keeping HIV status a secret (66.0%). Conversely, the three lowest percentages for the stigma management strategies which were used least by PIWH were forgiveness to oneself, relatives, and situation (12.6%), creating ulterior reasons (hiding the true reasons) to explain their health condition and/or illness (13.5%), and being selective in choosing friends or community (13.5%).

This study found the reasons respondents managed HIV stigma were to decrease and/or avoid stress (68.8%), to live like normal people who do not have HIV (57.7%), to transform negative thoughts to positive thoughts (55.3%), and to maintain good health (44.7%). The source of information to manage HIV stigma was from self-study and included searching the internet, TV, health promotion literature, socialization (68.4%) and the lowest percentage was from friends (20.5%). Moreover, people who helped respondents to manage HIV stigma were mostly initiative respondents (66.0%) and friends as the lowest percentage (22.8%). The majority of the respondents (96.3%) stated having effective stigma management strategies and 65.6% of respondents expressed being satisfied with their stigma management strategies. The first most effective was praying (28.8%) and the first least effective was staying alone (21.9%).

The Strengths and Limitations of the Study

In regards to the strengths of this study, first of all, this is the forerunner study on HIV stigma experience and management strategies with a sufficient number of samples. In addition, the data were collected from three hospitals and a private clinic from the region with the highest number of cases of HIV/AIDS in Bali and may reflect the experience and management strategies among PIWH in Bali, Indonesia. Since the SMSC was not examined for the content validity by experts, it may be limited in measuring the target construct of stigma management.

Challenges and Lesson Learned from the Study

HIV/AIDS is a very sensitive issue. Ethical approval and permission letter in each study setting is very important for this population. Techniques in approaching respondents must be considered carefully in particular regarding the socio-cultural factor of each location.

In this study, there were several challenging processes in the data collection phase: 1) difficult to find respondents who wanted to join and who had to be accompanied by a nurse, doctor, or counselor, 2) the building of mutual trust between the researcher and respondent due to the first meeting between the researcher and respondent, 3) respondent with a low level of education background (e.g., no education or not finished primary school) had to be accompanied while filling in the questionnaires which often had to be slowly read and explained in regards to the meaning of statement, 4) respondent did not have enough time, so that the researcher had to manage the time wisely and explain clearly about the purpose of the study, and 5) the researcher had to checked the completion of the questionnaires before letting

the respondent go back to home or work due to some respondents not completely filling in the questionnaires.

The researcher learnt a valuable lesson from this study in that the strategies to approach respondents were unique and different for each PIWH as they each had their own experiences about stigma experience and management. Attitudes of always listening, empathy, never judging or stigmatizing, being open-minded, respecting the socio-cultural factors, being polite, and good communication are needed and very important for this population. These attitudes are needed to prevent the risk of conflict during data collection.

Implications and Recommendations

Nursing practice. The finding of this study showed a moderate level of stigma experience among PIWH, wherein the subscale of self-acceptance had the highest mean score. Most respondents felt uncomfortable in telling anyone, including family and co-workers about their HIV status. It reflects that the nurses should concern to the confidentiality of PIWH's HIV status and build the process of trust between the nurse and PIWH.

Praying was the most common and the first most effective used stigma management strategy in this study. The nurse should be aware of the religiosity and spirituality of a person, especially in the country which has a strong faith to God and religion. The nurse can suggest to PIWH to do religious or spiritual activities, especially praying or having faith in God when the PIWH have negative feelings regarding stigma. Furthermore, creating a booklet as a manual tool to help to prevent stigma for PIWH in nursing practice is recommended. The booklet needs to include

general information of HIV/AIDS, the stigma attached to HIV, the social response towards PIWH, and strategies to manage HIV stigma based on the list of stigma management strategies that were found in this study.

Nursing education. This finding contributes to evidence-based nursing. It will be fruitful especially for bachelor nursing students to know about how to approach and interact with PIWH in the clinical practice. It also reflects that nursing students should improve empathy, open-mindedness, and careful communication with PIWH. In addition, workshops or training to be HIV counselor for nurses is needed based on current evidence about the strategies to manage the stigma. The findings of 37 stigma management strategies could be used as evidence in the workshops or training to help HIV nurse counselor in educating PIWH to manage their stigma.

Nursing research. Due to the results of this study, it appears that religion and culture are linked to stigma management strategies which exceed the objective in this study, so that the research on exploring the relationship between stigma and religion and culture could be conducted in the further study. In addition, a study on the correlation between HIV stigma experience and demographic characteristics is still needed, especially in Indonesia. Moreover, a future study could be conducted on the effect of HIV stigma management strategies on stigma reduction among PIWH.

References

- Aggarwal, S., Yu, L., Hasjim, B., Lee, D. H., Kim, E., Lee, J. B., . . . Diamond, C. (2018). Stigma and negative self-perception of young people living with human immunodeficiency virus in Bandung, Indonesia: A case series. *International Health, 10*, 401-403. doi: 10.1093/inthealth/ihy031
- Agung, D. A. G., Kanto, S., Wisadirana, D., & Ruja, I. N. (2017). Menyama braya as social capital of Hindu and Muslim community: A case study in Bali-Indonesia. *International Journal of West Asian Studies, 9*(1), 159-166. doi: 10.22583/ijwas.2017.09.01.12
- Ajong, A. B., Njotang, P. N., Nghoniji, N. E., Essi, M. J., Yakum, M. N., Agbor, V. N., & Kenfack, B. (2018). Qualification and factors associated with HIV-related stigma among persons living with HIV/AIDS on antiretroviral therapy at the HIV-day care unit of the Bamenda Regional Hospital, North West Region of Cameroon. *Globalization and Health, 14*(56). doi: 10.1186/s12992-018-0374-5
- Albright, J., & Fair, C. D. (2018). “Now I know I love me”: The trajectory to self-acceptance among HIV positive adults in a Southeastern U.S. Community Center. *SAGE Open, 1*-12. doi: 10.1177/2158244018804963
- Anderson, B., Braxton, S., Dunham, E., Imker, H., & Rimkus, K. (2016). Should we keep everything forever? Determining long-term value of research data. Retrieved from <https://pdfs.semanticscholar.org/d412/61f880ab2f37191bf671fd803a258effd605.pdf>
- Arnold, M. P., Benton, A., Loveluck, J., Skipper, S., & Sprague, L. (2016). The U.S. people living with HIV stigma index: Michigan, Wave I findings, 2014-2016. Retrieved from <http://www.stigmaindex.org/sites/default/files/reports/Michigan%20Stigma%20Index%20%20Report%202016.pdf>

- Arrey, A. E., Bilsen, J., Lacor, P., & Deschepper, R. (2015). "It's my secret": Fear of disclosure among Sub-Saharan African migrant women living with HIV/AIDS in Belgium. *PLoS ONE*, *10*(3). doi: 10.1371/journal.pone.0119653
- Aryal, R P. (2017). HIV stigma and discrimination management in Pokhara, Nepal. *Janapriya Journal of Interdisciplinary Studies*, *6*. doi: 10.3126/jjis.v6i0.19312
- Bartlett, J. E., Kotrlik, J. W., & Higgins, C. C. (2001). Organizational research: Determining appropriate sample size in survey research. *Information Technology, Learning, and Performance Journal*, *19*(1), 43-50.
- Beaulieu, M., Adrien, A., Potvin, L., Dassa, C., & Comite, PWIH. (2014). Stigmatizing attitudes towards people living with HIV/AIDS: Validation of a measurement scale. *BMC Public Health*, *14*. Retrieved from <http://www.biomedcentral.com/1471-2458/14/1246>
- Bello, I. O. M., Kabakama, S., Baisley, K., Francis, S.C., & Jones, D. W. (2019). Reported oral and anal sex among adolescents and adults reporting heterosexual sex in sub-Saharan Africa: A systematic review. *Reproductive Health*, *16*(48). doi: 10.1186/s12978-019-0722-9
- Berger, B. E., Ferrans, C. E., & Lashley, F. R. (2001). Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale. *Research in Nursing & Health*, *24*, 518-529. Retrieved from <https://onlinelibrary.wiley.com/doi/epdf/10.1002/nur.10011>
- Breitbart, W. (2018). Forgiveness. *Palliative Support Care*, *16*(3), 244-245. doi: 10.1017/S1478951518000408
- Caliari, J. D. S., Teles, S. A., Reis, R. K., & Gir, E. (2017). Factor related to the perceived stigmatization of people living with HIV. *Revista Da Escola De Enfermagem University of Sao Paulo*, *51*. doi: 10.1590/S1980-220X2016046703248

- Canadian Association for HIV/AIDS Research. (2008). Ethics issues for Canadian HIV/AIDS researchers in international settings. Retrieved from <https://www.cahr-acrv.ca/wp-content/uploads/2012/10/cahrreportfinal.pdf>
- Carlos, S., del Burgo, C. L., Burgueno, E., Martinez-Gonzalez, M. A., Osorio, A., Ndarabu, A., . . . de Irala, J. (2016). Male condom use, multiple sexual partners and HIV: A prospective case-control study in Kinshasa (DRC). *AIDS Care*. doi: 10.1080/09540121.2016.1258450
- Chakraborty, P. (2014). The law of karma and salvation. *International Journal of Humanities & Social Science Studies*, 1(3), 193-195. Retrieved from <http://oaji.net/articles/2014/1115-1417595573.pdf>
- Chenard, C. (2007). The impact of stigma on the self-care behaviors of HIV-positive gay men striving for normalcy. *Journal of the Association of Nurses in AIDS Care*, 18(3), 23-32. doi: 10.1016/j.jana.2007.03.005
- Chidrawi, H. C., Greeff, M., Temane, Q. M., & Doak, C. M. (2016). HIV stigma experiences and stigmatisation before and after an intervention. *Health SA Gesondheid*, 21, 196-205. doi: 10.1016/j.hsag.2015.11.006
- Chung, M. S. (2016). Relation between lack of forgiveness and depression: The moderating effect of self-compassion. *Psychological Report*, 0(0), 1-13. doi: 10.1177/0033294116663520
- Coleman, J. D., Tate, A. D., Gaddist, B., & White, J. (2016). Social determinants of HIV-related stigma in faith-based organizations. *American Journal of Public Health*, 106(3), 492-496. doi: 10.2105/AJPH.2015.302985
- Copstead, Lee Ellen, and Jacquelyn L. Banasik. (2010). *Pathophysiology*. 4th Edition. Canada: Saunders Elsevier
- Cuca, Y. P., Asher, A., Okonsky, J., Kaihura, A., Rose, C. D., & Webel, A. (2017). HIV stigma and social capital in women living with HIV. *Journal of the Association of Nurses in AIDS Care*, 28(1), 45-54. doi: 10.1016/j.jana.2016.09.001

- Culbert, G. J., Earnshaw, V. A., Wulanyani, N. M. S., Wegman, M. P., Waluyo, A., & Altice, F. L. (2015). Correlates and experiences of HIV stigma in prisoners living with HIV in Indonesia: A mixed-method analysis. *Journal of the Association of Nurses in AIDS Care*, 26(6), 743-757. doi: 10.1016/j.jana.2015.07.006
- Daftary, A. (2012). HIV and tuberculosis The construction and management of double stigma. *Social Science & Medicine*, 74, 1512-1519. doi: 10.1016/j.socscimed.2012.01.027
- Denpasar AIDS Commission. (2016). Cases situation of HIV/AIDS in Bali Province. Retrieved from <https://kpa.denpasarkota.go.id/data/Data%20Kasus%20HIV%20AIDS%20kumulatif%201987%20sampai%20dengan%20Tahun%202016.pdf>. (In Indonesian).
- Directorate General of Disease Control and Environmental Health, Ministry of Health, Republic of Indonesia. (2017). Statistic Case of HIV/AIDS in Indonesia reported until December 2016. Retrieved from spiritia.or.id/Stats/stat2016.xls. (In Indonesian).
- Directorate General of Disease Control and Environmental Health, Ministry of Health, Republic of Indonesia. (2018). Statistic Case of HIV/AIDS in Indonesia reported until December 2017. Retrieved from siha.depkes.go.id/portal/files.../Laporan_HIV_AIDS_TW_4_Tahun_2017__1_.pdf. (In Indonesian).
- Dodd, M., Janson, S., Facion, N., Faucett, J., Froelicher, E. S., Humphreys, J., . . . Taylor, D. (2001). Advancing the science of symptom management. *Journal of Advanced Nursing*, 33, 668-676. doi: 10.1046/j.1365-2648.2001.01697.x
- Donnelly, L. R., Bailey, L., Jessani, A., Postnikoff, J., Kerston, P., & Brondani, M. (2016). Stigma experiences in marginalized people living with HIV seeking health services and resources in Canada. *Journal of the Association of Nurses in AIDS Care*, 27(6), 768-783. doi: 10.1016/j.jana.2016.07.003

- Earnshaw, V. A., & Chaudoir, S. R. (2009). From conceptualizing to measuring HIV stigma: A review of HIV stigma mechanism measures. *AIDS Behavior, 13*(6), 1160-1177. doi: 10.1007/s10461-009-9593-3
- Earnshaw, V. A., Lang, S. M., Lippitt, M., Jin, H., & Chaudoir, S. R. (2015). HIV stigma and physical health symptoms: Do social support, adaptive coping, and/or identity centrality act as resilience resources?. *AIDS and Behavior, 19*(1), 41-49. doi: 10.1007/s10461-014-0758-3
- Ekstrand, M. L., Ramakrishna, J., Bharat, S., & Heylen, E. (2013). Prevalence and drivers of HIV stigma among health providers in urban India: Implications for interventions. *Journal of the International AIDS Society, 16*(Suppl 2). doi: 10.7448/IAS.16.3.18717
- European Institusi for Asian Studies. (2017). Indonesia: A model of tolerance, pluralism, and harmony. Retrieved from http://www.eias.org/wp-content/uploads/2016/03/EIAS_Event_Report_Indonesia_07.11.2017.pdf
- Fauci, A. S. (2006). 2005 Robert H. Ebert memorial lecture emerging and re-emerging infectious disease: The perpetual challenge. Retrieved from <https://www.milbank.org/wp-content/files/documents/0601fauci/0601Fauci.pdf>
- Fauk, N. K., Merry, M. S., Sigilipoe, M. A., Putra, S., & Mwanri, L. (2017). Culture, social networks and HIV vulnerability among men who have sex with men in Indonesia. *PLoS ONE 12*(6): e0178736. doi: 10.1371/journal.pone.0178736
- Fazeli, P. L., Turan, J. M., Budhwani, H., Smith, W., Raper, J. L., Mugavero, M. J., & Turan, B. (2017). Moment-to-moment within-person associations between acts of discrimination and internalized stigma in people living with HIV: An experience sampling study. *Stigma Health, 2*(3), 216-228. doi: 10.1037/sah0000051
- Frye, V., Paige, M. Q., Gordon, S., Matthews, D., Musgrave, G., Kornegay, M., . . . Koblin, B. A. (2017). Developing a community-level anti-HIV/AIDS stigma and homophobia intervention in New York city: The project CHHANGE

- model. *Evaluation and Program Planning*, 63, 45-53. doi: 10.1016/j.evalprogplan.2017.03.004
- Goffman, E. (1963). *Stigma: Note on management of spoiled identity*. Englewood Cliffs, New Jersey: Prentice-Hall.
- Gohain, Z., & Halliday, M. A. L. (2014). Internalized HIV-stigma, mental health, coping and perceived social support among people living with HIV/AIDS in Aizawl District: A pilot study. *Psychology*, 5, 1794-1812. doi: 10.4236/psych.2014.515186
- Greff, M., Uys, L. R., Holzemer, W. L., Makoae, L. N., Dlamini, P. S., Kohi, T. W., . . . Phetlhu, R. D. (2008). Experiences of HIV/AIDS stigma of persons living with HIV/AIDS and nurses involved in their care from five African countries. *Africa Journal of Nursing and Midwifery*, 10(1), 78-108. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2801161/pdf/nihms121149.pdf>
- Hao, C., & Liu, H. (2015). Actor and partner effect of perceived HIV stigma on social network components among people living with HIV/AIDS and their caregivers. *Global Health Promotion*, 22(2), 40-52. doi: 10.1177/1757975914537321
- Harapan, H., Khalilullah, S. A., Anwar, S., Putra, R. P., Zia, M., Novianty, F., . . . Yani, M. (2015). HIV-related stigmatized attitudes among health care providers in Aceh, Indonesia: The findings from a very low HIV case-load region. *Polish Annals of Medicine*, 22, 74-81. doi: 10.1016/j.poamed.2015.05.003
- Helms, C. B., Turan, J. M., Atkins, G., Kempf, M. C., Clay, O. J., Raper, J. L., . . . Turan, B. (2017). Interpersonal mechanism contributing to the association between HIV-related internalized stigma and medication adherence. *AIDS Behavior*, 21(1), 238-247. doi: 10.1007/s10461-016-1320-2

- Hlongwa, P. (2016). Current ethical issues in HIV/AIDS research and HIV/AIDS care. *Oral Diseases* 22(Suppl.1), 61-65. doi: 10.1111/odi.12391
- Hutson, S. P., Darlington, C. K., Hall, J. M., Heidel, R. E., & Gaskins, S. (2018). Stigma and spiritual well-being among people living with HIV/AIDS in Southern Appalachia. *Issues in Mental Health Nursing*, 1096-4673. doi: 10.1080/01612840.2017.1423426
- Ibrahim, K., & Songwathana, P. (2009). Cultural care for people living with HIV/AIDS in Muslim Communities in Asia: A literature review. *Thai Journal of Nursing Research*, 13(2), 148-156. Retrieved from <https://www.tci-thaijo.org/index.php/PRIJNR/article/view/6445/5619>
- Ismail, R. (2015). Stigma in women living with HIV in Jakarta, Indonesia. Abstract retrieved from <https://digital.lib.washington.edu/researchworks/handle/1773/26392?show=full>
- Israel, G. D. (1992). Determining sample size. *University of Florida: Florida Cooperative Extension Service*.
- Jaggers, J. R., & Hand, G. A. (2016). Health benefits of exercise for people living with HIV: A review of the literature. *American Journal of Lifestyle Medicine*. doi: 10.1177/1559827614538750
- Januraga, P. P., Reekie, J., Mulyani, T., Lestari, B. W., Iskandar, S., Wisaksana, R., . . . Kaldor, J. M. (2018). The cascade of HIV care among key population in Indonesia: A prospective cohort study. *Lanset HIV*. doi: 10.1016/S2352-3018(18)30148-6
- Joint United Nations Programme on HIV/AIDS. (2017). Press release: UNAIDS announces nearly 21 million people living with HIV now on treatment. Retrieved from http://www.unaids.org/sites/default/files/20171120_PR_RTH_SA_final_v2.pdf

- Joint United Nations Programme on HIV/AIDS. (2018). UNAIDS Data 2018. Geneva: UNAIDS. Retrieved from http://www.unaids.org/sites/default/files/media_asset/unaids-data-2018_en.pdf
- Judgeo, N., & Moalusi, K. P. (2014). My secret: The social meaning of HIV/AIDS stigma. *SAHARA Journal*, *11*(1), 76-83. doi: 10.1080/17290376.2014.932302
- Kamitani, E., Chen, J. L., Portillo, C., Tokumoto, J., Rose, C. D. (2018). Shortened and culturally appropriate HIV stigma scale for Asians living with HIV in the United States: Psychometric analysis. *Journal of the Association of Nurses in AIDS Care*, *29*(4), 560-569. doi: 10.1016/j.jana.2018.02.007
- Karamouzian, M., Akbari, M., Haghdoost, A. A., Setayesh, H., & Zolala, F. (2015). "I am dead to them": HIV-related stigma experienced by people living with HIV in Kerman, Iran. *Journal of the Association of Nurses in AIDS Care*, *26*(1), 46-56. doi: 10.1016/j.jana.2014.04.005
- Kingori, C., Nkansah, M. A., Haile, Z., Darlington, K-A., & Basta, T. (2017). Factors associated with HIV related stigma among college students in the Midwest. *AIMS Public Health*, *4*(4), 347-363. doi: 10.3934/publichealth.2017.4.347
- Komalasari, R. (2012). Perceptions on HIV/AIDS-related stigma and discrimination in Sukabumi prison in Indonesia, an exploratory study. Retrieved from <http://edepot.wur.nl/298095>
- Kumar, N., Unnikrishnan, B., Thapar, R., Mithra, P., Kulkarni, V., Holla, R., . . . Kumar, A. (2017). *Journal of the International Association of Providers of AIDS Care*, *16*(3), 226-232. doi: 10.1177/2325957415569309
- Kumar, S., Mohanraj, R., Rao, D., Murray, K. R., & Manhart, L. E. (2015). Positive coping strategies and HIV-related stigma in South India. *AIDS Patient Care and STDs*, *29*(3). doi: 10.1089/apc.2014.0182
- Lee, K. A., Gay, C., Portillo, C. J., Coggins, T., Davis, H., Pullinger, C. R., & Aouizerat, B. E. (2009). Symptom experience I HIV-infected adults: A

- function of demographic and clinical characteristics. *Journal Pain Symptom Management*, 38(6), 882-893. doi: 10.1016/j.jpainsymman.2009.05.013
- Lemin, A. S., Rahman, M. M., & Pangarah, C. A. (2018). Factors affecting intention to disclose HIV status among adult population in Sarawak, Malaysia. *Journal of Environmental and Public Health*. doi: 10.1155/2018/2194791
- Li, L., Lin, C., & Ji, P. (2017). Gendered aspects of perceived and internalized HIV-related stigma in China. *Women Health*, 57(9), 1031-1043. doi: 10.1080/03630242.2016.1235075
- Li, M. J., Murray, J. K., Suwanteerangkul, J., & Wiwatanadate P. (2014). Stigma, social support, and treatment adherence among HIV-positive patients in Chiang Mai, Thailand. *AIDS Education Prevention*, 26(5), 471-483. doi: 10.1521/aeap.2014.26.5.471
- Li, Z., Hsieh, E., Morano, J. P., & Sheng, Y. (2016). Exploring HIV-related stigma among HIV-infected men who have sex with men in Beijing, China: A correlation study. *AIDS Care*, 28(11), 1394-1401. doi: 10.1080/09540121.2016.1179713
- Li, Z., Morano, J. P., Khoshnood, K., Hsieh, E., & Sheng, Y. (2018). HIV-related stigma among people living with HIV/AIDS in rural Central China. *BMC Health Services Research*, 18. doi: 10.1186/s12913-018-3245-0
- Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, 27, 363-385. Retrieved from <http://www.jstor.org/stable/2678626>
- Link, B. G., Yang, L. H., Phelan, J. C., & Collins, P. Y. (2004). Measuring mental illness stigma. *Schizophrenia Bulletin*, 30(3), 511-541. doi: 10.1093/oxfordjournals.schbul.a007098
- Logie, C. H., James, L., Tharao, W., & Loutfy, M. R. (2011). HIV, gender, race, sexual orientation, and sex work: A qualitative study of intersectional stigma experienced by HIV-positive women in Ontario, Canada. *PLoS Medicine*, 8(11). doi: 10.1371/journal.pmed.1001124

- Lunze, K., Lioznov, D., Cheng, D. M., Nikitin, R. V., Coleman, S. M., Bridden, C., Samet, J. H. (2017). HIV stigma and unhealthy alcohol use among people living with HIV in Russia. *AIDS Behavior*, *21*(9), 2609-2617. doi: 10.1007/s10461-017-1820-8
- Mahajan, A. P., Sayles, J. N., Patel, V. A., Remien, R. H., Ortiz, D., Szekeres, G., & Coates, T. J. (2008). Stigma in the HIV/AIDS epidemic: A review of the literature and recommendation for the way forward. *AIDS*, *22*(Suppl 2), S67-S79. doi: 10.1097/01.aids.0000327438.13291.62
- Malave, S., Ramakrishna, J., Heylen, E., Bharat, S., & Ekstrand, M. L. (2014). Differences in testing, stigma, and perceived consequences of stigmatization among heterosexual men and women living with HIV in Bengaluru, India. *AIDS Care*, *26*(3), 396-403. doi: 10.1080/09540121.2013.819409
- Martin, L. A., Vosvick, M., & Riggs, S. A. (2012). Attachment, forgiveness, and physical health quality of life in HIV+ adults. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV*, *24*(11), 1333-1340. doi: 10.1080/09540121.2011.648598
- Mawar, N., Sahay, S., Pandit, A., & Mahajan, U. (2005). The third phase of HIV pandemic: Social consequences of HIV/AIDS stigma & discrimination & future needs. *Indian Journal of Medical Research*, *122*, 471-484. Retrieved from <http://medind.nic.in/iby/t05/i12/ibyt05i12p471.pdf>
- Merati, T., Supriyadi, & Yuliana, F. (2005). The disjunction between policy and practice: HIV discrimination in health care and employment in Indonesia. *AIDS Care: Psychological and Socio-medical Aspects of HIV/AIDS*, *17*:S2, 175-179. doi: 10.1080/09540120500119932
- Mhode, M., & Nyamhanga, T. (2016). Experiences and impact of stigma and discrimination among people on antiretroviral therapy in Dar es Salaam: A qualitative perspective. *AIDS Research and Treatment*, doi: 10.1155/2016/7925052

- Miller, C. T., Solomon, S. E., Varni, S. E., Hodge, J. J., Knapp, F. A., & Bunn, J. Y. (2016). A transactional approach to relationships over time between perceived HIV stigma and psychological and physical well-being of people with HIV. *Social Science & Medicine*, *162*, 97-105. doi: 10.1016/j.socscimed.2016.06.025
- Mimiaga, M. J., Bogart, L. M., Thurston, I. B., Santostefano, C. M., Closson, E. F., Skeer, M. R., Biello, K. B., & Safren, S. A. (2019). Positive strategies to enhance problem-solving skills (STEPS): A pilot randomized, controlled trial of a multicomponent, technology-enhanced, customizable antiretroviral adherence intervention for HIV-infected adolescents and young adults. *AIDS Patient Care and STDs*, *33*(1). doi: 10.1089/apc.2018.0138
- Ministry of Health, Republic of Indonesia. (2015). *Strategic Planing Ministry of Health 2015-2019*. Retrieved from http://www.nationalplanningcycles.org/sites/default/files/planning_cycle_repository/indonesia/restra_2015_translated_1.pdf
- Morens, D. M., & Fauci, A. S. (2013). Emerging infectious diseases: Threats to human health and global stability. *PLOS Pathogens*, *9*(7). doi: 10.1371/journal.ppat.1003467
- Mutahar, R., Najmah, Yenni. (2011). Determinants of Indonesian people attitudes towards people living with HIV/AIDS (PLWHA). *International Journal of Public Health Research*, *224-228*. Retrieved from http://journalarticle.ukm.my/3557/1/special%2520issue%25202011_30.pdf
- Muthuswamy, V. (2005). Ethical issues in HIV/AIDS research. *Indian Journal Medical*, *121*, 601-610.
- Nugroho, A., Erasmus, V., Coulter, R. W. S., Koirala, S., Nampaisan, O., Pamungkas, W., & Richardus, J. H. (2018) Driving factors of retention in care among HIV-positive MSM and transwomen in Indonesia: A cross-sectional study. *PLoS ONE* *13*(1): e0191255. doi: 10.1371/journal.pone.0191255

- Okoror, T. A., Falade, C. O., Walker, E. M., Olorunlana, A., & Anaele, A. (2016). Social context surrounding HIV diagnosis and construction of masculinity: A qualitative study of stigma experiences of heterosexual HIV positive men in southwest Negeria. *BMC Public Health*, *16*(507). doi: 10.1186/s12889-016-3165-z
- Pakasi, D. T., & Kartikawati, R. (2013). Between needs and taboos: Sexuality and reproductive health education for high school students. *Makara Health Seri*, *17*(2), 79-87. doi: 10.7454/msk.v17i2.xxxx. (In Indonesian).
- Pala, A. N., Villano, P., & Clinton, L. (2017). Attitude of heterosexual men and women toward HIV negative and positive gay men. *Journal of Homosexuality*, *64*(13), 1778-1792. doi: 10.1080/00918369.2016.1265358
- Parker, R., & Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: A conceptual framework and implications for action. *Social Science & Medicine*, *57*, 13-24. Retrieved from https://ac.els-cdn.com/S0277953602003040/1-s2.0-S0277953602003040-main.pdf?_tid=c4f5aa43-9b12-48a9-87bc-a49523c9d7f9&acdnat=1542867763_17e7b0675eb12b203ba22a78e57b837c
- Peltzer, J. N., Ogawa, L., Tusher, S., Farnan, R., & Gerkovich, M. M. (2016). A qualitative description of HIV-infected African American women's experiences of psychological distress and their coping strategies. *Journal of the Association of Nurses in AIDS Care*. doi: 10.1016/j.jana.2016.09.010
- Permata, Y. L. (2014). HIV prevention in female sex workers in Indonesia: A literature review. Retrieved from http://bibalex.org/baifa/Attachment/Documents/ilgf5RvuSR_20161108165552909.pdf
- Pescosolido, B. A., & Martin, J. K. (2015). The stigma complex. *Annual Review of Sociology*, *41*, 87-116. doi: 10.1146/annurev-soc-071312-145702

- Polit, D. F., & Beck, C. T. (2006). The content validity index: Are you sure you know what's being reported? critique and recommendation. *Research in Nursing & Health, 29*, 489-497. doi: 10.1002/nur.20147
- Polit, D. F., & Beck, C. T. (2012). *Nursing research: Generating and assessing evidence for nursing practice*. Wolters Kluwer Health/Lipincott Williams and Wilkins.
- Polit, D. F., & Beck, C. T. (2017). *Nursing research: Generating and assessing evidence for nursing practice*. Wolters Kluwer Health/Lipincott Williams and Wilkins.
- Pourmarzi, D., Khoramirad, A., & Gaeni, M. (2017). Perceived stigma in people living with HIV in Qom. *Journal of Family and Reproductive Health, 11*(4), 202-210. Retrieved from <http://jfrh.tums.ac.ir>
- Power, J., Westle, A., Dowsett, G. W., Lucke, J., Tucker, J. D., Sugarman, J., . . . Richmond, J. (2018). Perceptions of HIV cure research among people living with HIV in Australia. *PLoS ONE, 13*(8). doi: 10.1371/journal.pone.0202647
- Pretorius, J. B., Greeff, M., Freeks, F. E., & Kruger, A. (2016). A HIV stigma reduction intervention for people living with HIV and their families. *Health SA Gesondheid, 21*, 187-195. doi: 10.1016/j.hsag.2015.11.005
- Prinshloo, C. D., & Greeff, M. (2015). A community "Hub" network intervention for HIV stigma reduction: A case study. *Journal of the Association of Nurses in AIDS Care*. doi: 10.1016/j.jana.2015.10.007
- Radhakrishna, R., B. (2007). Tips for developing and testing questionnaires/instruments. Retrieved from <https://www.joe.org/joe/2007february/tt2.php>
- Rael, C. T., Dieguez, A. C., Norton, R., Thorley, E., Giguere, R., Sheinfil, A., & Rios, J. L. (2017). Identifying strategies to cope with HIV-related stigma in a group of women living with HIV/AIDS in the Dominican Republic: A qualitative study. *AIDS Behavior, 21*(9), 2589-2599. doi: 10.1007/s10461-016-1654-9

- Reinius, M., Wettergren, L., Wiklander, M., Svedhem, V., Ekstrom, A. M., & Eriksson, L. E. (2017). Development of a 12-item short version of the HIV stigma scale. *Health and Quality of Life Outcomes*, *15*. doi: 10.1186/s12955-017-0691-z
- Rote, N. S. (2012). Infection and defects in mechanism of defense. In Huether, S. E. Editor, & McCance, K. L. Editor (Eds.), *Understanding Pathophysiology* (165-203). Missouri: Elsevier Mosby.
- Rueda, S., Mitra, S., Chen, S., Gogolishvili, D., Globerman, J., Chambers, L., . . . Rourke, S. B. (2016). Examining the associations between HIV-related stigma and health outcomes in people living with HIV/AIDS: A series of meta-analyses. *BMJ Open*. doi: 10.1136/bmjopen-2016-011453
- Ruffell, S. (2017). Stigma kills! The psychological effects of emotional abuse and discrimination towards a patient with HIV in Uganda. *BMJ Case Report*. doi: 10.1136/bcr-2016-218024
- Santos, M. M. L.D., Kruger, P., Mellors, S. E., Wolvaardt, G., & Ryst. (2014). An exploratory survey measuring stigma and discrimination experienced by people living with HIV/AIDS in South Africa: The people living with HIV stigma index. *BMC Public Health*, *14*(80). doi: 0.1186/1471-2458-14-80
- Sayles, J. N., Hays, R. D., Sarkisian, C. A., Mahajan, A. P., Spritzer, K. L., & Cunningham, E. (2008). Development and psychometric assessment of a multidimensional measure of internalized HIV stigma in a sample of HIV-positive adults. *AIDS Behavior*, *12*(5), 748-758. doi: 10.1007/s10461-008-9375-3
- Sayles, J. N., Wong, M. D., Kinsler, J. J., Martins, D., Cunningham, W. E. (2009). The association of stigma with self-reported access to medical care and antiretroviral therapy adherence in persons living with HIV/AIDS. *Journal of General Internal Medicine*, *24*(10), 1101-1108. doi: 10.1007/s11606-009-1068-8

- Sengupta, S., Banks, B., Jonas, D., Miles, M. S., & Smith, G. C. (2011). HIV intervention to reduce HIV/AIDS stigma: A systematic review. *AIDS and Behavior, 15*(6), 1075-1087. doi: 10.1007/s10461-010-9847-0
- Sengupta, S., Strauss, R. P., Miles, M. S., Isler, M. R., Banks, B., & Smith, G. C. (2010). A conceptual model exploring the relationship between HIV stigma and implementing HIV clinical trials in rural communities of North Carolina. *North Carolina Medical Journal, 71*(2), 113-122. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3037544/pdf/nihms269092.pdf>
- Sitiari, N. W., Suprapti, N. W. S., Sintaasih, D. K., & Sudibya, I. G. A. (2016). Exploration of Bali's cultural values and entrepreneurial orientation in relation to cooperative managers in Bali. *European Journal of Business and Management, 8*(14). Retrieved from <https://pdfs.semanticscholar.org/ccb7/f7dfb6e7599aad9fb76b938f918aee4b2113.pdf>
- Smith, A. L. F., & Santis, J. P. D. (2012). Exploring the concept of HIV-related stigma. *Nursing Forum, 47*(3), 153-165. doi: 10.1111/j.1744-6198.2011.00235.x
- Srithanaviboonchai, K., Chariyalertsak, S., Nontarak, J., Assanangkornchai, S., Kessomboon, P., Putwatana, P., . . . Aekplakorn, W. (2017). Stigmatizing attitudes towards people living with HIV among general adult Thai population: Result from the 5th Thai National Health Examination Survey (NHES). *PLoS ONE, 12*(11). doi: 10.1371/journal.pone.0187231
- Statistic Indonesia, National Population and Family Planning Board, Ministry of Health, & ICF International. (2013). *Indonesia Demographic and Health Survey 2012*. Jakarta, Indonesia: BPS, BKKBN, Kemenkes, and ICF International.
- Stuenkel, D. L., & Wong, V. K. (2013). Stigma. Retrieved from http://www.jblearning.com/samples/076375126x/larsen_ch03_ptr.pdf

- Stutterheim, S. E., Sicking, L., Brands, R., Baas, I., Roberts, H., Brakel, W. H., . . . Bos, A. E. R. (2014). Patient and provider perspectives on HIV and HIV-related stigma in Dutch health care setting. *AIDS Patient Care and STDs*, 28(12). doi: 10.1089/apc.2014.0226
- Sulung, N., & Asyura, R. (2019). The analysis of spirituality of patients with HIV/AIDS in taking lesson and self-acceptance. *Indian Journal of Palliative Care*, 25(2), 232-235. doi: 10.4103/IJPC.IJPC_203_18
- Suresh, K. P., & Chandrashekara, S. (2012). Sample size estimation and power analysis for clinical research studies. *Journal of Human Reproductive Sciences*, 5(1). doi: 10.4103/0974-1208.97779
- Suwitha, I. P. G. (2016). Local genius in the rural area of Bali: From 'Menyama-Braya' to multiculturalism. *International Journal of Linguistics, Language, and Culture*, 2(2), 68-76. doi: 10.6084/m9.figshare.3426524
- Suyanti, T. S., Keliat, B. A., & Helena, N. (2018). Effect of logo-therapy, acceptance, commitment therapy, family psychoeducation on self-stigma, and depression on housewives living with HIV/AIDS. *Enfermeria Clinica*, 28(1), 98-101. doi: 10.1016/S1130-8621(18)30046-9
- Tang, K., & Ti-Chen, W. (2018). HIV and religion in HIV-infected Asians and their families: A qualitative study. *Applied Nursing Research*, 44, 18-24. doi: 10.1016/j.apnr.2018.09.003
- Thapa, S., Hannes, K., Cargo, M., Buve, A., Aro, A. R., & Mathei, C. (2017). Buildig a conceptual framework to study the effect of HIV stigma-reduction intervention strategies on HIV test uptake: A scoping review. *Journal of the Association of Nurses in AIDS Care*, 28(4), 545-560. doi: 10.1016/j.jana.2017.04.004
- The Joanna Briggs Institute. (2016). Checklist for analytical cross-sectional studies. Retrieved from The Joanna Briggs Institute critical appraisal tools for use in

JBI systematic review. website: <http://joannabriggs.org/research/critical-appraisal-tools.html>

- Tran, B. X., Phan, H. T., Latkin, C. A., Nguyen, H. L. T., Hoang, C. L., Ho, C. S. H., & Ho, R. C. M. (2019). Understanding global HIV stigma and discrimination: Are contextual factors sufficiently studied? (GAP research). *International Journal of Environment Research and Public Health*, *16*. doi: 10.3390/ijerph16111899
- Tzemis, D., Forrest, J. I., Puskas, C. M., Zhang, W., Orchard, T. R., Palmer, A. K., . . . Hogg, R. S. (2013). Identifying self-perceived HIV-related stigma in a population accessing antiretroviral therapy. *AIDS Care*, *25*(1). doi: 10.1080/09540121.2012.687809
- Utami, S., Sawitri, A. A. S., Putra, I. W. G. A. E., Astuti, P. A. S., Januraga, P. P., Wulandari, L. P. L., . . . Mathers, B. (2017). Mortality among people living with HIV on antiretroviral treatment in Bali, Indonesia: incidence and predictors. *International Journal of STD & AIDS*, *0*(0), 1-9. doi: 10.1177/0956462417692942
- Valles, J. R., Molina, Y., & Dirkes, J. (2013). Stigma towards PLWHA: The role of internalized homosexual stigma in Latino gay/bisexual male and transgender communities. *AIDS Education and Prevention Journal*, *25*(3), 179-189. doi: 10.1521/aeap.2013.25.3.179
- Waluyo, A., Culbert, G. J., Levy, J., & Norr, K. F. (2015). Understanding HIV-related sigma among Indonesian nurses. *Journal of the Association of Nurses in AIDS Care*, *26*(1), 69-80. doi: 10.1016/j.jana.2014.03.001
- Wasti, S. P., van Teijlingen, E., Simkhada, P., Randall, J., Baxter, S., Kirkpatrick, P., & Ge, V. S. (2012). Factors influencing adherence to antiretroviral treatment in Asian developing countries: A systematic review. *Tropical Medicine and International Health*, *17*(1), 71-81. doi: 10.1111/j.1365-3156.2011.02888.x

Wyrod, R. (2011). Masculinity and the persistence of AIDS stigma. *Culture Health Sexuality, 13*(4), 443-456. doi: 10.1080/13691058.2010.542565

Yu, C. H., Chiu, Y. C., Cheng, S. F., & Ko, N. Y. (2018). HIV stigma and spiritual care in people living with HIV. [Abstract]. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/29790134>

Appendix A

Informed Consent

Informed consent form for person infected with HIV in Bali, Indonesia, which are invited to participate in a research study entitled **“Experience and Management of Stigma Among Persons Infected With HIV in Bali, Indonesia”**.

Researcher	Advisor
Mr. Nyoman Agus Jagat Raya Master of Nursing Science (International Program), Faculty of Nursing, Prince of Songkla University, Thailand Phone: +6285737422205 Email: jagatraya.bali@gmail.com	Assoc. Prof. Dr. Kittikorn Nilmanat Adult and Elderly Nursing Department, Faculty of Nursing, Prince of Songkla University, Thailand Email: kittikorn.n@psu.ac.th

Miss Chayanit Pudpong

Center for Social and Behavioral Sciences Institutional Review Board

Prince of Songkla University, Hat Yai, Songkhla, Thailand

Email: chayantit.p@psu.ac.th

Phone number: +6674286475

My name is Nyoman Agus Jagat Raya, I am nursing educator in Nursing Study Program of Udayana University. Now, I am prepared master nursing student at Faculty of Nursing, Prince of Songkla University, Thailand. I am conducting a study entitled “Experience and management of stigma among persons infected with HIV in Bali, Indonesia”. It accordingly expected that the research conclusion will be added to raise the nursing intervention and quality of health care for person infected with HIV. This study has been accepted by the Human Research Ethics Center for Social Behavioral Sciences Institutional Review Board Prince of Songkla University, Thailand. It also has been approved by the Research Ethics Committee Faculty of Medicine, Udayana University/Sanglah Hospital Denpasar. You are asked to be a respondent in this study. When you determine to be respondent in this study, I will begin the following instruction:

Explanation procedures

You will be given a set of self-report consist of three part questionnaires: 1) Demographic Characteristics Form Persons Infected With HIV (DCFPIWH), 2) The 28-Item Internalized HIV Stigma Scale, and 3) Stigma Management Strategies Checklist (SMSC) and you have given the opportunity to answer the entire self-report questionnaires for approximately 15-25 minutes. The researcher will be guiding you

during the process of completing the self-report questionnaire. You allowed asking the researcher if there is question might not understand.

Risk and Comfort

There is no big risk or harm for this study. Despite, filling the questionnaires may make you consume more time with us. However, the researcher will check your condition prior to fill the questionnaires. In the case that something wrong or make you feel discomfort, you can stop for a while, take a rest, and consult the researcher to help you directly. The researcher will provide contact information such as telephone number, so that you can spend your extra time with us.

Benefit

This research will help you to express your voice related stigma experience and stigma management. Further, the result of this study will help nurses and other health care provider to understand the stigma experience and management among persons infected with HIV. It also will be helpful for the future study related to stigma experience and management among persons infected with HIV.

Confidentiality

All information and your feedback in the present study will be endured confidential and anonymous. Moreover, only the researcher, research advisor, and research committee in this research are eligible to access the data. Neither your name nor any identifying information will be used in the report of study.

Participation and withdrawal from respondent

Your participation in this project is voluntary. You have the right, either to participate or not to participate in this study due to the researcher will give you 10 minutes to think before deciding to participate or refuse from this study. You can also have the right to withdraw from your participation at any time without any consequences or penalty, impact on your receiving service, or impact in any medical treatment or routine care. In conclusion, if you have any question or suggestion you can directly contact me by phone +6285737422205.

Finally, if you are agree to participate in this research, please kindly sign your name on the consent form. Thank you very much for your kind cooperation.

Nyoman Agus Jagat Raya
Researcher

Appendix B

Informed Consent Form

Topic : Experience and Management of Stigma Among Persons Infected With HIV in Bali, Indonesia

Researcher : Nyoman Agus Jagat Raya (prepared master nursing student at Faculty of Nursing, Prince of Songkla University, Thailand)

Respondent's nick name :

Age :

Respondent's Consent

I,(initial name), was informed of the detail of the research topic about stigma and was approved that no part of my personal information and research finding be going to be individually discovered to the public. If any concern or issues come up, I can discuss them with the researcher. I have the right to withdraw from this study at any time without any impact on any medical service and treatment. I am willing to participate in this study, and here is my signature. With consideration above, here is I decide without the force from any side, accordingly, I agree to participate as a respondent in this study.

Respondent

Witness

Signature : initial name

Signature :

Date :

Date :

I gave the detailed information of the research topic "Experience and management of stigma among persons infected with HIV in Bali, Indonesia" to the respondent. I provide the opportunity to the respondent to ask any question and provide the required answer.

Signature : (Researcher)

Date :

Appendix C

Demographic Characteristics Form Persons Infected With HIV (DCFPIWH)

Instruction: Please give the check list (√) on the box appropriate to your answer where indicated and fill in the blank area.

- 1) Age: 18-35 years 36-55 years 56-64 years
- 2) Gender: Male Female
- 3) Sexual orientation: Heterosexual Homosexual Bisexual
- 4) Religion: Hindu Islam Christian Buddhist Catholic others ...
- 5) Race/ethnicity: Balinese Javanese Betawi/Jakarta Sundanese
 Chinese others
- 6) Level of education:
 no education primary school junior high school
 senior high school university/graduate
- 7) Employment status before HIV diagnosis
 Unemployed Employed :
 Self-employee/business
 Private employee
 Government employee
 please specify other profession:
- 8) Employment status after HIV diagnosis
 Unemployed Employed:
 Self-employee/business
 Private employee
 Government employee
 please specify other profession:
- 9) Age at HIV diagnosis:
 ≤18 years 19-35 years 36-50 years 50-64 years
- 10) Duration after HIV diagnosis: years
- 11) Place of residence: Rural Urban
- 12) Who do you live with? Alone Family Friends Spouse

Appendix D

The 28-Item Internalized HIV Stigma Scale

Instruction:

Check (✓) the statement that reflects to your stigma experience.

none of the time = 0; a little of the time = 1; some of the time = 2; most of the time = 3; all of the time = 4

No	Item	none of the time	a little of the time	some of the time	most of the time	all of the time
		0	1	2	3	4
1.	HIV is different than other diseases like cancer because people with HIV are judged.					
2.	People assume I have done something bad to get HIV.					
3.	Society looks down on people who have HIV.					
4.	People think that if you have HIV then you got what you deserve.					
5.	People blame me for having HIV.					
6.	People assume I slept around because I have HIV.					
7.	People think that if you have HIV you do not deserve to have children.					
8.	People are afraid to let someone with HIV adopt a child.					
9.	People think I am a bad person because I have HIV.					
10.	Medical providers assume people with HIV sleep around.					
11.	People lose their jobs because they have HIV.					
12.	People think you can't be a good parent if you have HIV.					
13.	I am concerned if I go to the HIV clinic someone I know might see me.					
14.	I am concerned if I have physical changes from the HIV medicines people will know I have HIV.					

No	Item	none of the time	a little of the time	some of the time	most of the time	all of the time
		0	1	2	3	4
15.	I am concerned if I go to an AIDS organization someone I now might see me.					
16.	I am concerned people will find out I have HIV by looking at my medical paperwork.					
17.	I am concerned that if I am sick people I know will find out about my HIV.					
18.	Nurses and doctors treat people who have HIV as if they are contagious.					
19.	Nurses and doctors dislike caring for patients with HIV.					
20.	I feel abandoned by family members because I have HIV.					
21.	People treat me as less than human now that I have HIV.					
22.	People avoid me because I have HIV.					
23.	People I am close to are afraid they will catch HIV from me.					
24.	I feel like I am an outsider because I have HIV.					
25.	I feel ashamed to tell other people that I have HIV.					
26.	I am comfortable telling everyone I know that I have HIV.					
27.	My family is comfortable talking about my HIV.					
28.	It is important for a person to keep HIV a secret from co-workers.					

Indonesian Version of the 28-Item Internalized HIV Stigma Scale

(28-Item Skala Stigma HIV yang Terinternalisasi)

Cek (√) pernyataan **stigma pada diri sendiri** di bawah ini apabila Anda pernah berpikir terjadi pada diri Anda sendiri dan/atau pernah mengalaminya.

tidak sama sekali = **0**; jarang = **1**; beberapa kali/ kadang-kadang = **2**; sering = **3**; setiap saat/waktu = **4**

Nomer	Pernyataan	tidak sama sekali	jarang	beberapa kali/ kadang-kadang	sering	setiap saat/waktu
		0	1	2	3	4
1.	Orang dengan HIV sering dihakimi karena HIV berbeda dengan jenis penyakit lainnya, seperti kanker.					
2.	Orang berasumsi bahwa saya telah melakukan sesuatu yang buruk sehingga terjangkit HIV.					
3.	Masyarakat memandang rendah orang dengan HIV.					
4.	Orang berpikir bahwa jika seseorang terjangkit HIV, maka dia akan mendapatkan apa yang layak diterimanya.					
5.	Orang menyalahkan saya karena terjangkit HIV.					
6.	Orang berasumsi bahwa saya tidur dengan siapa saja karena saya memiliki HIV.					
7.	Orang berasumsi bahwa bila seseorang memiliki HIV, maka orang tersebut tidak layak memiliki keturunan.					
8.	Orang takut membiarkan seseorang dengan HIV untuk mengadopsi anak.					
9.	Orang berpikir saya orang yang jahat karena saya memiliki HIV.					

Nomer	Pernyataan	tidak sama sekali	jarang	beberapa kali/ kadang-kadang	sering	setiap saat/waktu
		0	1	2	3	4
10.	Petugas kesehatan berasumsi orang dengan HIV bersedia tidur dengan siapa saja.					
11.	Orang kehilangan pekerjaannya karena memiliki HIV.					
12.	Orang berpikir bahwa Anda tidak bisa menjadi orang tua yang baik bila Anda memiliki HIV.					
13.	Saya khawatir orang melihat saya bila saya pergi ke klinik HIV.					
14.	Saya khawatir orang akan mengetahui saya memiliki HIV bila terjadi perubahan fisik pada diri saya akibat mengkonsumsi obat HIV.					
15.	Saya khawatir orang akan melihat saya bila saya mengunjungi organisasi AIDS.					
16.	Saya khawatir orang akan mengetahui saya memiliki HIV dengan melihat catatan medis saya.					
17.	Saya khawatir orang yang saya kenal akan mengetahui status HIV saya bila saya terlihat sakit.					
18.	Perawat dan dokter memperlakukan orang HIV seakan-akan mereka menular.					
19.	Perawat dan dokter tidak suka merawat pasien dengan HIV.					
20.	Saya merasa ditelantarkan anggota keluarga karena saya memiliki HIV.					
21.	Sekarang orang					

Nomer	Pernyataan	tidak sama sekali	jarang	beberapa kali/ kadang-kadang	sering	setiap saat/waktu
		0	1	2	3	4
	memperlakukan saya kurang manusiawi karena saya memiliki HIV.					
22.	Orang menghindari saya karena saya memiliki HIV.					
23.	Orang dekat saya takut tertular HIV dari saya.					
24.	Saya merasa menjadi terasingkan karena saya memiliki HIV.					
25.	Saya merasa malu memberitahukan orang bahwa saya memiliki HIV.					
26.	Saya merasa nyaman memberitahu setiap orang bahwa saya memiliki HIV.					
27.	Keluarga saya nyaman membicarakan tentang HIV yang saya miliki.					
28.	Sangat penting bagi seseorang untuk merahasiakan status HIV-nya dari teman kerjanya.					

Reliability Test Result of the 28-Item Internalized HIV Stigma Scale

HIV Stigma (all subscales)

Reliability Statistics

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.924	.923	28

Subscale I: Stereotypes

Reliability Statistics

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.918	.917	12

Subscale II: Disclosure concerns

Reliability Statistics

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.959	.961	5

Subscale III: Social-relationships

Reliability Statistics

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.914	.913	7

Subscale IV: Self-acceptance

Reliability Statistics

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.405	.385	4

Appendix E

Calculation Formula the 28-Item Internalized HIV Stigma Scale

Sayles et al. (2008) mentioned in their study about the range of mean score the 28-Item Internalized HIV Stigma Scale were transformed linearly to a 0-100. First of all, we should know that the 28-Item Internalized HIV Stigma Scale has 4 subscales, namely stereotypes (12 items), disclosure concerns (5 items), social relationships (7 items), and self-acceptance (4 items). To transformed 0-4 (five-point Likert scale) into range 0-100 based on the calculation formula. Culbert et al. (2015) who adopted the 28-Item Internalized HIV Stigma Scale explained this formula was calculated subscale score by the number of items in each subscale. Overall scores were calculated by adding subscale scores and dividing by 4 so that subscales were weighted equally. For example, one respondent showed the checklist score result in Table 12 as follows:

Table 12

An Example of One Respondent Checklist Score Result

I	R	I	R	I	R	I	R
1	4	13	2	18	4	25	4
2	4	14	3	19	3	26	2
3	3	15	4	20	4	27	2
4	3	16	4	21	4	28	4
5	4	17	3	22	4		
6	3			23	4		
7	4			24	4		
8	3						
9	3						
10	4						
11	4						
12	3						

Note. I = Item; R = Respondent's answer

Table 13

Calculation per Subscale and Total Stigma: An Example

Item	Formula	Result
Stereotypes (12 items)	6 x 4 = 24 6 x 3 = 18 Total = 42 / 12	3.50
Disclosure concerns (5 items)	1 x 2 = 2 2 x 3 = 6 2 x 4 = 8 Total = 16 / 5	3.20
Social relationships (7 items)	1 x 3 = 3 6 x 4 = 24 Total = 27 / 7	3.86
Self-acceptance (4 items)	2 x 4 = 8 2 x 2 = 4 Total = 12 / 4	3.00
Total score		$(3.50 + 3.20 + 3.86 + 3.00) / 4$ $= 13.56 / 4 = 3.39$

To transform scale range 0-4 to be 0-100 based on an example above is in table as follows:

Table 14

Transformed Score 0-4 to be 0-100

Subscale	Possible score	Actual score	Transformed linearly	Actual score in range 0-100
Stereotypes	0-4	3.50	x 25	87.50
Disclosure concerns	0-4	3.20	x 25	80.00
Social relationships	0-4	3.86	x 25	96.50
Self-acceptance	0-4	3.00	x 25	75.00
Total stigma	0-4	3.39	x 25	84.75

Appendix F

Stigma Management Strategies Open Questions (SMSOQ)

Open Questions:

1. What were your strategies to manage the stigma? If you do not want to be stigmatized, what will you do?
2. Why did you manage the stigma?
3. Where did you get information to manage the stigma?
4. Who helped you to manage the stigma?
5. How about your satisfaction and effectiveness;
 - a. Do you think that you satisfy with your stigma management?
 - b. Does your stigma management strategies were effective or ineffective?
 - c. What was the most effective strategy?
 - d. What was the least effective strategy?

Appendix G

Stigma Management Strategies Checklist (SMSC)

Instruction:

Answer this question and give this symbol (√) on the available column if it reflects to your stigma management strategies experience.

1. What were your strategies to manage the stigma? (*you are allowed choose or check (√) for more than one answer*)
 - hanging out or traveling with friends or relatives
 - joining the people living with HIV/AIDS (PLWHA) community
 - working
 - sharing information with or educating others about HIV
 - seeking the support:
 - friend
 - family
 - spouse
 - health care provider
 - trying to live life and coming to terms with being a PLWH
 - trying to do not care about what people say or do
 - accepting whatever happens as the will of God
 - pursuing hobby or activity, such as;
 - please mentioned*
 - being alone in quiet room or place
 - praying
 - reading holy book
 - meditation or *Yoga*
 - positive thinking
 - sleeping enough
 - stay healthy–adherence to treatment
 - focus on the here and now
 - creating ulterior reason (hiding the true reasons) to explain your health condition and/or illness
 - relocation–moving from one area to another
 - forgiveness (to myself, relatives, e.g., spouse, and situation)
 - feeling oneself to be lucky and better than others in some ways
 - looking to the future
 - ignoring negative feelings
 - trying to be nice to people (doing good to others)
 - preoccupation with other things or activities
 - seeking information from health care providers
 - others, please mentioned:
 -
 -
 -

If you do not want to be stigmatized, what will you do? *(you are allowed choose or check (✓) for more than one answer)*

- behaving like ‘normal’ people who do not have HIV
- doing good or behaving well in line with the concept of *Karma*
- abstain from discussion of topics related to HIV
- practicing silence and solitude
- keep HIV status a secret
- being selective when choosing friends or community where to live or work
- changing the topic when people discuss HIV
- hiding ARV drugs or changing their package labels
- others, please mentioned:

.....

2. Why did you manage the stigma? *(you are allowed choose or check (✓) for more than one answer)*

- to transform negative thoughts to positive thoughts
- to decrease and/or stress
- to maintain good health
- to live like ‘normal’ people that do not have HIV
- others, please mentioned:

.....

3. Where did you get information to manage the stigma? *(you are allowed choose or check (✓) for more than one answer)*

- self-study from *(please mentioned)*
- doctor/nurse/counselor
- close friend/best friend
- spouse
- family
- others, please mentioned:

.....

4. Who helped you to manage the stigma? *(you are allowed choose or check (✓) for more than one answer)*

- myself
- doctor/nurse/counselor
- close friend/best friend
- spouse
- family

others, please mentioned:

.....
.....
.....

5. Are you satisfied with your stigma management strategies?

Satisfied Quite satisfied Not satisfied

6. Do you think your stigma management strategies were effective or ineffective?

Effective Ineffective

7. Which one is the most effective of your stigma management strategies?

.....
.....

8. Which one is the least effective of your stigma management strategies?

.....
.....

Daftar Strategi Memanajemen Stigma (Indonesian Version)

Petunjuk:

Jawablah pertanyaan ini dan beri simbol ini (√) pada kolom yang tersedia jika jawaban tersebut merefleksikan (sesuai) dengan pengalaman Anda dalam strategi manajemen stigma (pikiran atau perasaan negatif).

1. Apakah strategi Anda dalam manajemen stigma? (*Anda diperbolehkan memilih atau menandai (√) lebih dari satu jawaban*)

- jalan-jalan atau berpergian dengan teman atau kerabat dekat
- gabung dengan komunitas orang dengan HIV/AIDS (ODHA)
- bekerja
- berbagi edukasi dan informasi tentang HIV ke orang lain
- mencari dukungan ke:
 - teman
 - keluarga
 - pasangan
 - penyedia layanan kesehatan (tenaga kesehatan)
- mencoba untuk bertahan hidup dan menerima diri sendiri sebagai ODHA
- mencoba untuk tidak peduli (tidak fokus pada perkataan atau perlakuan orang)
- menerima apapun yang Tuhan berikan pada diri saya
- melakukan hobi atau aktivitas yang saya sukai, seperti (*mohon disebutkan*)
- menyendiri di kamar atau tempat yang sepi
- berdoa (sembahyang)
- membaca kitab suci
- meditasi atau Yoga
- berpikir positif
- cukup tidur
- menjaga kesehatan tubuh (misal: patuh terhadap perawatan)
- fokus pada kehidupan disini dan saat ini
- membuat alasan lain untuk menjelaskan tentang status kesehatan saya
- pindah lokasi – pindah dari satu lokasi ke lokasi lainnya
- memaafkan diri sendiri, kerabat (misal: pasangan), dan situasi
- saya merasa lebih beruntung dan lebih baik daripada hidup orang lain
- berpikir jangka panjang (masa depan)
- melupakan semua perasaan negatif
- mencoba bersikap baik (misal: melakukan hal positif terhadap orang lain)
- fokus pada hal atau aktivitas lainnya
- mencari informasi dari tenaga kesehatan
- strategi lainnya, mohon disebutkan:

.....

Jika Anda tidak ingin distigma, apa yang akan Anda lakukan? (*Anda diperbolehkan memilih atau menandai (√) lebih dari satu jawaban*)

- bersikap seperti orang normal lainnya yang tanpa HIV
- melakukan hal baik kepada masyarakat (melakukan *Karma* baik)
- tidak berkomentar jika orang lain berdiskusi tentang HIV di depan saya
- tetap diam dan menjauh dari orang lain
- menjaga status HIV tetap rahasia
- selektif dalam memilih teman atau komunitas
- mengganti topik pembicaraan jika orang sekitar membahas HIV
- menyembunyikan ARV atau merubah label obat ARV
- strategi lainnya, mohon disebutkan:

.....

2. Mengapa Anda manajemen stigma? (*Anda diperbolehkan memilih atau menandai (√) lebih dari satu jawaban*)

- agar merubah pemikiran negatif menjadi pemikiran positif
- agar mengurangi stres
- agar menjaga kesehatan tubuh (tidak lagi sakit atau kambuh)
- agar hidup seperti orang lainnya tanpa mengidap HIV
- alasan lainnya, mohon disebutkan:

.....

3. Dimana Anda mendapatkan informasi mengenai cara manajemen stigma? (*Anda diperbolehkan memilih atau menandai lebih (√) dari satu jawaban*)

- dari diri sendiri (mencari tahu atau belajar sendiri)
- dokter/perawat/konselor
- teman dekat/sahabat
- pasangan
- keluarga
- sumber lainnya, mohon disebutkan:

.....

4. Siapakah yang membantu Anda dalam manajemen stigma? (*Anda diperbolehkan memilih atau menandai lebih (√) dari satu jawaban*)
- diri sendiri
 - dokter/perawat/konselor
 - teman dekat/sahabat
 - pasangan
 - keluarga
 - sumber lainnya, mohon disebutkan:
.....
.....
.....
5. Apakah Anda puas dengan strategi manajemen stigma yang Anda lakukan selama ini?
- puas cukup puas tidak puas
6. Apakah Anda pikir strategi manajemen stigma yang Anda efektif atau tidak efektif?
- efektif tidak efektif
7. Dari seluruh jawaban strategi manajemen stigma Anda, manakah yang paling efektif?
-
.....
8. Dari seluruh jawaban strategi manajemen stigma Anda, manakah yang paling tidak efektif?
-
.....

Appendix H

List of Translators for Back Translation of the Instruments

The translation of the instrument: The 28-Item Internalized HIV Stigma Scale was done by three bilingual translators who were familiar with both English and Bahasa Indonesia (Indonesian language) and have nursing background.

1. Ns. Made Rini Damayanti S., S.Kep., MNS

Community Nursing, Udayana University, Bali, Indonesia.

She translated the instrument of English into Bahasa Indonesia version.

2. Ns. Dara Febriana, S.Kep., MSc., PhD

Adult and Gerontological Nursing, Syiah Kuala University, Indonesia.

She translated the instrument of Bahasa Indonesia into English version.

3. I Gede Putu Darma Suyasa, S.Kp., MNg., PhD

Institute of Health Sciences of Bali, Indonesia.

He checked the discrepancies both the original instrument and the English back translation to ensure the usable instrument.

Appendix I

List of Experts for Content Validity of the Instruments

The content validity of Demographic Characteristics Form Persons Infected With HIV (DCFPIWH) and Stigma Management Strategies Open Questions (SMSOQ) were validated by the following three experts; one expert from Adult and Gerontological Nursing and two experts from Indonesia who have experience research of HIV stigma and taking care patients with HIV infection and AIDS.

1. Asst. Prof. Dr. Tippamas Chinnawong

Adult and Gerontological Nursing, Faculty of Nursing, Prince of Songkla University, Thailand.

2. Assoc. Prof. Agung Waluyo, S.Kp, MSc, PhD

Medical and Surgical Nursing, Faculty of Nursing, University of Indonesia, Indonesia; Senior Researcher of HIV Stigma in Indonesia.

3. Ns. Ni Made Ratni, S.Kep

Head Nurse of HIV (VCT) Outpatient Department at Sanglah Hospital, Bali, Indonesia.

Appendix J

Calculation Sample Size

The total HIV cases in Bali in 2016 was 1,539 cases (Denpasar AIDS Commission, 2016). According to Bartlett, Kotrlik, & Higgins (2001), the sample size for descriptive study is based on this formula:

$$n_0 = \frac{(t)^2 * (s)^2}{(d)^2}$$

Note. n_0 = sample size; t = normal deviated for two-tailed alternative at level of significance (e.g. 5% = 1.96; 1% = 2.58); s = estimate standard deviation; d = margin of error for mean (point of scale * margin of error).

This formula is used for sample size if continuous data will be used in data analysis. This study, the data will use 5-point-Likert scale. However, if the required sample size more than 5% of the population, so that the researcher should correction formula to calculate the final sample size as follows:

$$n_1 = \frac{n_0}{1 + n_0/Population}$$

Note. n_1 = required return sample size because sample > 5% of population; n_0 = previous sample size.

Level of significant used 5% (1.96) for this study. Margin of error is 5% (0.05). Standard deviation from previous descriptive study was 1.8 for personalized stigma from Lunze et al. (2017). The number of minimum sample size for this study is:

$$n_0 = \frac{(1.96)^2 * (1.8)^2}{(5 * 0.05)^2} = 199.04 = 199 \text{ subjects}$$

Due to the n_0 is more than 5% of total population (5% of 1,539 = 76.95 = 77), so that the total sample size using the second formula.

$$n_1 = \frac{199}{1 + 199/1,539} = 176.26 = 176 \text{ subjects}$$

According to Suresh & Chandrashekara (2012) and Israel (1992), the sample size formula provides number of responses that need commonly 10% to be obtained to anticipate for missing, losses to follow-up, and withdrawals. Therefore, the sample size for this study is 215 subjects.

Appendix K
Additional Data Analysis

Table 15

Frequency and Percentage Level of HIV Stigma Experience (N = 215)

Dimension	Low	Moderate	High
	n (%)	n (%)	n (%)
Stereotypes	67 (31.2)	79 (36.7)	69 (32.1)
Disclosure concerns	64 (29.8)	83 (38.6)	68 (31.6)
Social-relationships	57 (26.5)	99 (46.0)	59 (27.4)
Self-acceptance	58 (27.0)	99 (46.0)	58 (27.0)
Total stigma	71 (33.0)	73 (34.0)	71 (33.0)

Table 16

Descriptive Statistic of 28-Item Internalized HIV Stigma Scale (N = 215)

28-Item Internalized HIV Stigma Scale	None of the time	A little of the time	Some of the time	Most of the time	All of the time	M (SD)	Median (IQR)
	n (%)	n (%)	n (%)	n (%)	n (%)		
1. HIV is different than other diseases like cancer because people with HIV are judged.	72 (33.5)	35 (16.3)	53 (24.6)	46 (21.4)	9 (4.2)	36.75 (31.75)	50 (75)
2. People assume I have done something bad to get HIV.	58 (27.0)	26 (12.1)	58 (27.0)	59 (27.4)	14 (6.5)	43.50 (32.25)	50 (75)
3. Society looks down on people who have HIV.	31 (14.4)	31 (14.4)	37 (17.2)	92 (42.8)	24 (11.2)	55.50 (31.25)	75 (50)
4. People think that if	56	31	66	47	15	42.25	50 (75)

	28-Item Internalized HIV Stigma Scale	None	A little	Some	Most	All of	<i>M</i> (SD)	Median (IQR)
		of the time n (%)	of the time n (%)	of the time n (%)	of the time n (%)	the time n (%)		
	you have HIV then you got what you deserve.	(26.0)	(14.4)	(30.7)	(21.9)	(7.0)	(31.50)	
5.	People blame me for having HIV.	73 (33.9)	28 (13.0)	44 (20.5)	55 (25.6)	15 (7.0)	39.75 (34.00)	50 (75)
6.	People assume I slept around because I have HIV.	75 (34.9)	33 (15.3)	48 (22.3)	49 (22.8)	10 (4.7)	36.75 (32.50)	25 (75)
7.	People think that if you have HIV you do not deserve to have children.	90 (41.9)	28 (13.0)	36 (16.7)	49 (22.8)	12 (5.6)	34.25 (34.25)	25 (75)
8.	People are afraid to let someone with HIV adopt a child.	98 (45.6)	42 (19.5)	35 (16.3)	33 (15.3)	7 (3.3)	27.75 (30.75)	25 (50)
9.	People think I am a bad person because I have HIV.	92 (42.8)	30 (13.9)	42 (19.5)	41 (19.1)	10 (4.7)	32.25 (32.75)	25 (50)
10.	Medical providers assume people with HIV sleep around.	137 (63.7)	33 (15.3)	24 (11.2)	15 (7.0)	6 (2.8)	17.5 (27.25)	0 (25)
11.	People lose their jobs because they have HIV.	108 (50.2)	28 (13.0)	37 (17.2)	35 (16.3)	7 (3.2)	27.25 (31.75)	0 (50)
12.	People think you can't be a good parent if you have HIV.	115 (53.5)	28 (13.0)	35 (16.3)	27 (12.5)	10 (4.7)	25.50 (31.75)	0 (50)
13.	I am concerned if I go to the HIV clinic someone I know might see me.	63 (29.3)	22 (10.2)	40 (18.6)	66 (30.7)	24 (11.2)	46.00 (35.50)	50 (75)
14.	I am concerned if I have physical changes from the HIV medicines people will know I have HIV.	54 (25.1)	30 (13.9)	44 (20.5)	60 (27.9)	27 (12.6)	47.25 (34.75)	50 (75)
15.	I am concerned if I go to an AIDS	73 (33.9)	30 (14.0)	41 (19.1)	54 (25.1)	17 (7.9)	39.75 (34.50)	50 (75)

	28-Item Internalized HIV Stigma Scale	None of the time	A little of the time	Some of the time	Most of the time	All of the time	<i>M</i> (SD)	Median (IQR)
		n (%)	n (%)	n (%)	n (%)	n (%)		
	organization someone I now might see me.							
16.	I am concerned people will find out I have HIV by looking at my medical paperwork.	48 (22.3)	31 (14.4)	46 (21.4)	60 (27.9)	30 (14.0)	49.25 (34.25)	50 (50)
17.	I am concerned that if I am sick people I know will find out about my HIV.	50 (23.2)	24 (11.2)	47 (21.9)	69 (32.1)	25 (11.6)	49.50 (33.75)	50 (50)
18.	Nurses and doctors treat people who have HIV as if they are contagious.	160 (74.4)	32 (14.9)	19 (8.8)	3 (1.4)	1 (0.5)	9.75 (18.75)	0 (25)
19.	Nurses and doctors dislike caring for patients with HIV.	179 (83.2)	21 (9.8)	12 (5.6)	2 (0.9)	1 (0.5)	6.50 (16.00)	0 (0)
20.	I feel abandoned by family members because I have HIV.	155 (72.1)	23 (10.7)	21 (9.8)	12 (5.6)	4 (1.8)	13.50 (25.00)	0 (25)
21.	People treat me as less than human now that I have HIV.	149 (69.3)	27 (12.6)	27 (12.6)	9 (4.2)	3 (1.3)	14.00 (24.00)	0 (25)
22.	People avoid me because I have HIV.	116 (54.0)	37 (17.2)	30 (14.0)	25 (11.6)	7 (3.2)	23.25 (30.00)	0 (50)
23.	People I am close to are afraid they will catch HIV from me.	109 (50.7)	40 (18.6)	29 (13.5)	29 (13.5)	8 (3.7)	25.25 (30.75)	0 (50)
24.	I feel like I am an outsider because I have HIV.	116 (54.0)	30 (14.0)	28 (13.0)	35 (16.3)	6 (2.7)	25.00 (31.50)	0 (50)
25.	I feel ashamed to tell other people that I have HIV.	39 (18.2)	19 (8.8)	34 (15.8)	68 (31.6)	55 (25.6)	59.50 (35.50)	75 (75)
26.	I am comfortable	143	36	23	9 (4.2)	4 (1.9)	85.50	100

	28-Item Internalized HIV Stigma Scale	None	A little	Some	Most	All of	<i>M</i> (SD)	Median (IQR)
		of the time n (%)	of the time n (%)	of the time n (%)	of the time n (%)	the time n (%)		
	telling everyone I know that I have HIV.*	(66.5)	(16.7)	(10.7)			(24.25)	(25)
27.	My family is comfortable talking about my HIV.*	134 (62.3)	29 (13.5)	29 (13.5)	21 (9.8)	2 (0.9)	81.75 (27.00)	100 (25)
28.	It is important for a person to keep HIV a secret from co- workers.	34 (15.8)	16 (7.4)	28 (13.1)	37 (17.2)	100 (46.5)	67.75 (37.50)	75 (50)

Note. * = Response scale values reversed for scoring.

Appendix L

Research Ethics Approval Letter

Certificate of Approval of Human Research Ethics (Prince of Songkla University)



Certificate of Approval of Human Research Ethics
Center for Social and Behavioral Sciences Institutional Review Board,
Prince of Songkla University

Document Number: 2019 NST - Qn 001

Research Title: The Experience and Management of HIV Stigma among HIV-Infected
Individuals in Bali, Indonesia

Research Code: PSU IRB 2019 – NST 005

Principal Investigator: Nyoman Agus Jagat Raya

Workplace: Master of Nursing Science (International Program), Faculty of Nursing,
Prince of Songkla University

Approved Document: 1. Human Subjects
2. Instrument
3. Invitation and Informed Consent

Approved Date: 2 April 2019

Expiration Date: 2 April 2021

This is to certify that the Center for Social and Behavioral Sciences Institutional Review Board, Prince of Songkla University approved for Ethics of this research in accordance with Declaration of Belmont.

Sununta Y.
.....
(Assoc. Prof. Dr. Sununta Youngwanichsetha)
Committee Vice-Chairman of Center for Social and Behavioral Sciences
Institutional Review Board, Prince of Songkla University

Ethical Approval for the Use of Human Subjects (Faculty of Medicine and Sanglah Hospital, Bali, Indonesia)



**RESEARCH ETHICS COMMITTEE
FACULTY OF MEDICINE, UDAYANA
UNIVERSITY/SANGLAH HOSPITAL DENPASAR**

Jalan P. Serangan Denpasar Bali (80114)

Telp. (0361) 227911-15 (P.227), (0361)244534

**ETHICAL APPROVAL
FOR THE USE OF HUMAN SUBJECTS**

No : 420/UN14.2.2.VII.14/LP/2019

The Research Ethics Committee of Faculty of Medicine, Udayana University/Sanglah Hospital, after conducting review based on Nuremberg Code and Helsinki Declaration of the research protocol entitled :

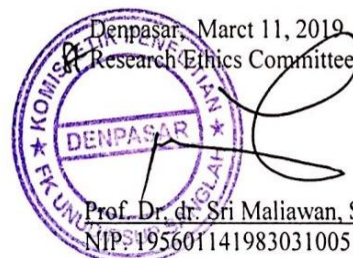
“The Experience and Management of HIV Stigma among HIV-Infected Individuals in Bali, Indonesia”

Submitted on January 29, 2019 by Ns. Nyoman Agus Jagat Raya, S.Kep.

has hereby declared that the above protocol whereby human subjects will be used, has been approved for implementation.

Please note that this *ethical approval* is for the period of 1 year since approved date.

Should there be any modification and/or extension of the study, the Principal Investigator is required to submit the protocol for approval. The progress and final summary reports should be submitted to The Research Ethics Committee, Faculty of Medicine, Udayana University/Sanglah Hospital.

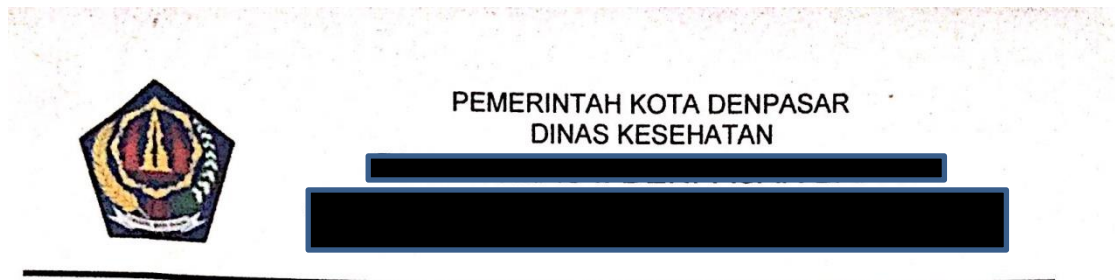


Prof. Dr. dr. Sri Maliawan, Sp.BS(K)
NIP:195601141983031005

Appendix M

Approval Permission Letter for Data Collection

Public Health Center in Denpasar



SURAT REKOMENDASI
Nomor : 070 / 480 /Puskesmas II D.B

Yang bertanda tangan di bawah ini :

Nama : **dr. Lanawati, M. Kes**
 NIP. : 19650918 199509 2 001
 Pangkat / Gol : Pembina (IV/a)
 Jabatan : Kepala [REDACTED]

Memberi Rekomendasi Kepada :

Nama : **Nyoman Agus Jagat Raya**
 Status Peneliti : Mahasiswa
 Alamat : Perumahan Griya Tansa Trisna, Jalan Mangga Dua No. 26 Dalung
 Bidang / Judul : **"The Experience and Management of HIV Stigma Among HIV-Infected Individuals in Bali, Indonesia"**
 Lokasi : [REDACTED]
 Jumlah Peserta : 1 (satu) orang
 Lama Penelitian : "2 (dua) bulan (01 Maret s.d 01 2019)

Untuk melaksanakan ijin penelitian , permintaan informasi dan data yang dibutuhkan.

Demikian surat Rekomendasi ini dibuat untuk dapat dipergunakan sebagaimana mestinya

Denpasar, 5 Maret 2019
 Kepala [REDACTED]
 (**dr. Lanawati . M.Kes**)
 NIP.19650918/199509 2 001

Tembusan :

1. Yang bersangkutan;
2. Arsip

Public Health Center in Badung



PEMERINTAH KABUPATEN BADUNG
DINAS KESEHATAN



SURAT REKOMENDASI
No : 441 / 418 / Pusk K. I

Yang bertanda tangan di bawah ini :

Nama : dr. Indira Pudi Asri
NIP : 19671023 199903 2003
Pangkat / Gol : Pembina / IV a
Jabatan : Kepala [REDACTED]

Memberikan rekomendasi izin kepada :

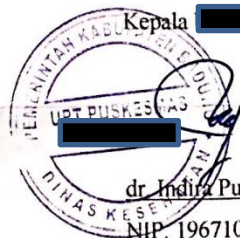
Nama : Nyoman Agus Jagat Raya
Status Peneliti : Mahasiswa S2
Alamat : Perumahan Griya Tansa Trisna, Jalan Mangga Dua No. 26 Dalung
Judul : *The Experience and Management of HIV Stigma among HIV-Infected Individuals in Bali, Indonesia*
Lokasi : [REDACTED]
Jumlah peserta : 1 (satu) orang
Lama penelitian : 2 bulan (15 Maret – 15 Mei 2019)

Untuk melaksanakan penelitian, permintaan informasi, dan data yang dibutuhkan.

Demikian surat rekomendasi izin penelitian ini dibuat untuk dapat dipergunakan sebagaimana mestinya.

Kuta, 12 Maret 2019

Kepala [REDACTED]



dr. Indira Pudi Asri

NIP. 19671023 199903 2003

Tembusan:

1. Yang bersangkutan
2. Arsip

Hospital in Denpasar



PEMERINTAH KOTA DENPASAR



Nomor : 070 / 888 / RSUDW Denpasar, 1 April 2019
 Lampiran : - Kepada
 Perihal : Ijin Rekomendasi/ Penelitian Yth. Kepala Badan Kesatuan Bangsa dan Politik
 Kota Denpasar.
 Jln. Beliton No. 1 Denpasar, Bali
 di-
 Tempat

Menunjuk surat saudara Nomor : 070/193/BKBP tanggal 26 Februari 2019, perihal permohonan ijin Penelitian mengenai "*The Experience and Management of HIV Stigma Among HIV-Infected Individuals in Bali, Indonesia*", atas nama saudara/i Nyoman Agus Jagat Raya dapat kami ijin sesuai dengan jadwal.

Adapun kontribusi yang dibebankan kepada mahasiswa yang bersangkutan sesuai dengan Perwali Kota Denpasar Nomor 33 Tahun 2014 sebagai berikut :

- Jasa Sarana :	1 bulan x 1 proposal x Rp. 50.000,-	Rp. 50.000,-
- Jasa Pelayanan :	1 bulan x 1 proposal x Rp. 50.000,-	Rp. 50.000,-
Jumlah		Rp. 100.000,-

Demikian kami sampaikan atas kerja sama dan perhatiannya diucapkan terima kasih.

A.n. Plt. Direktur [REDACTED]

[REDACTED] Denpasar
 Wakil Direktur
 Penunjang dan Pengembangan SDM
 [REDACTED]
 dr. Ida Ayu Aswari Dewi Yudarsana
 NPA SP Pembina
 NIP. 19661022 200312 2 002

Tembusan Kepada Yth :

1. Yang bersangkutan
2. Arsip

Hospital in Denpasar



**KEMENTERIAN KESEHATAN RI
DIREKTORAT JENDERAL PELAYANAN KESEHATAN**

**SURAT IJIN**

No: LB.02.01/XIV.2.2.11/1024 12019

Sesuai dengan Surat Keterangan Laik Etik (Ethical Clearance) No:420/UN.14.2.2.VII.14/LP/2019 yang dikeluarkan oleh Komisi Etik Penelitian Fakultas Kedokteran Universitas Udayana/Rumah Sakit Umum Denpasar, dengan ini diberikan Ijin Penelitian kepada:

Peneliti Utama : Ns. Nyoman Agus Jagat Raya, S.Kep
 Judul Penelitian : **THE EXPERIENCE AND MANAGEMENT OF HIV STIGMA AMONG HIV-INFECTED INDIVIDUALS IN BALI, INDONESIA**
 Prodi/Bagian/KSM : Fakultas Keperawatan, Departemen Keperawatan Dewasa dan Lansia (Program Internasional), Prince of Songkla University, Thailand
 Unit/Tempat Penelitian : Poliklinik VCT, Klinik Penyakit Tropik dan Infeksi Terpadu Nusa Indah Denpasar
 Masa Berlaku : **14 April 2019 s/d 10 Maret 2020**
 (sampai dengan masa berakhir Ethical Clearance)

Ijin diberikan untuk mengumpulkan data penelitian dengan kuisisioner yang disampaikan melalui petugas poliklinik VCT. Peneliti diwajibkan untuk memenuhi persyaratan sebagai berikut

- 1 Menyimpan Informed consent penelitian untuk pemeriksaan sewaktu – waktu.
- 2 Menyerahkan laporan perkembangan penelitian yang disyaratkan oleh Komisi Etik Penelitian FK UNUD Denpasar dan Bagian Diklit Denpasar, disertai daftar Rekam Medik dari sample penelitian (formulir laporan dapat diambil di Bagian Diklit)
- 3 Mengumpulkan hasil penelitian soft copy ke Bag Diklit Denpasar.

Demikian surat ijin ini kami buat untuk dapat dipergunakan sebagaimana mestinya.

15 April 2019
 A/ Direktur SDM dan Pendidikan
 Ka Bag Pendidikan dan Penelitian

I Putu Putra Wisada, SH,MM
 NIP-196304031983031002

Tembusan (foto copy) :
 1 Ka Poliklinik VCT Denpasar
 2 Yang Bersangkutan

Private Clinic in Kuta

[REDACTED] [REDACTED]

Nomor : 06 / III / 2019

To Nyoman Agus Jagat Raya

Based on first meeting on March 1, 2019 with Nyoman Agus Jagat Raya as principal investigator and according to ethical approval for the use of human subjects No: 420/UN 14.2.2.VII.14/LP/2019 and Badung Government permission for conducting research No: 070/273/Kesbang about his topic research *The Experience and Management of HIV Stigma among HIV-Infected Individuals in Bali, Indonesia*, has been approved for implementation in [REDACTED] to conduct his research. He can meet HIV patients if the patients want to meet him directly.

If you need any further information, please do not hesitate to contact us [REDACTED]

Kuta, March 12, 2019

[REDACTED]

Made Yogi O. Prasetya, MD

Appendix N

Author Permission for the 28-Item Internalized HIV Stigma Scale

Jagat Raya <jagatraya.bali@gmail.com>

Min, 9 Des
2018 04.03

kepada drhays, Ron_Hays

Dear Prof. Ron D. Hays,

First of all, I am sorry for disturbing your time and thank you for your time to read my email. My name is Jagat Raya. Currently, I am master student from Faculty of Nursing, Prince of Songkla University Thailand.

Actually, I have plan to conduct research about HIV-related stigma experience and management among HIV-infected individuals in Bali, Indonesia. I read your article with Dr. Sayles about development and psychometric assessment of internalized HIV stigma, and it is interested to me and it is fit with my study to measure level of stigma among HIV-infected individuals. Actually, I have contacted Dr. Sayles through the email, but the email can not send to the email on correspondent author. Therefore, I would like to ask your permission (as the team with Dr. Sayles) to use and modify some items of the 28-item measure of internalized HIV stigma regarding the sociocultural context in Indonesia. I also would like to translate to Indonesian version.

Would you mind if I use the 28-item measure of internalized HIV stigma for conducting my study? It will fruitful for HIV individuals and health care providers who work in HIV/AIDS area in Indonesia

Thank you for your kind attention.

Yours sincerely,
Jagat Raya

RONALD HAYS <drhays@ucla.edu>

Sab, 8 Des
2018 13.02

kepada Billy, Jennifer, saya

I have copied the relevant people.

Jagat Raya <jagatraya.bali@gmail.com>

Min, 9 Des
2018 04.20

kepada drhays

Dear Prof. Ronald Hays,

Thank you very much for your kind response. It will be fruitful for us to conduct the study.

Yours sincerely,
Jagat Raya

Cunningham, William <WCunningham@mednet.ucla.edu>

Sab, 8 Des
2018 13.14

kepada Jennifer, RONALD, saya

yes, u may use the instrument as described. i would be interested in any publications that result.

best of luck!

Jagat Raya <jagatraya.bali@gmail.com>

9 Des 2018
04.31

kepada WCunningham

Dear Prof. William E. Cunningham,

Thank you very much for your kind attention to us.

Yours sincerely,
Jagat Raya

VITAE

Name Mr. Nyoman Agus Jagat Raya

Student ID 6010420006

Educational Attainment

Degree	Name of Institution	Year of Graduation
Bachelor of Nursing	Udayana University	2013
Clinical Education Program (Nursing Profession)	Udayana University	2014

Scholarship Awards during Enrolment

Education fee and salary. Thailand's Education Hub for Southern Regions of ASEAN Countries (TEH-AC) scholarship award for Master's degree year 2017-2019.

Thesis grant. The Graduate School Dissertation Funding for Thesis, Prince of Songkla University.

Conference grant. Faculty of Nursing, Prince of Songkla University.

Reward during Enrolment

Nomination Best Poster Presentation on Conference of Thailand Nursing Honor Society and Sigma Theta Tau International Honor Society of Nursing, Phi Omega-at-Large Chapter (Moving Towards Global Health Leaders: A Call for Nurses) 2018, Asia Hotel, Bangkok, Thailand.

Working Experience

An orientation registered nurse in Adult Medical and Surgical Ward, Puri Raharja Hospital, Denpasar, Bali, Indonesia (2015).

A lecturer of Medical Surgical Nursing, Department of Nursing, Faculty of Medicine, Udayana University, Bali, Indonesia (2015 – present). e-mail: jagatraya.bali@gmail.com or jagatraya91@unud.ac.id

List of Publication and Proceeding

Raya, N. A. J., & Nilmanat, K. (2018). *Symptom Experienced by Adult HIV-Infected Patients: A Literature Review*. Oral presented at the First Academic Fair, Fulfilling the Royal Wish “Benefit of Mankind” 2018, Faculty of Nursing, Prince of Songkla University, Thailand.

Raya, N. A. J., & Nilmanat, K. (2018). *Assessment Tools of Symptom Experience among Adult HIV-Infected Patient: A Literature Review*. Poster presented at the Conference of Thailand Nursing Honor Society and Sigma Theta Tau International Honor Society of Nursing, Phi Omega-at-Large Chapter (Moving Towards Global Health Leaders: A Call for Nurses) 2018, Asia Hotel, Bangkok, Thailand.