

The Relationship Between Spiritual Meaning of The Experience of Illness and The Use of Coping Strategies in People Living With HIV/AIDS

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Abstract—This study aims to determine the relationship between the spiritual meaning of the experience of illness and coping strategies in people living with HIV/AIDS (PLWHA) at one hospital in Jakarta. The study used a cross-sectional design to PLWHA population with a sample size of 30 clients HIV positive, aged 28-29 years, who were willing to be respondents. The research instrument used questionnaires and data analysis with Chi-square test. The results of the study show that there is a relationship between the spiritual meaning of the experience of illness and coping strategies of PLWHA (p value 0.010). PLWHA who gave spiritual meaning to their illness experience in a positive way had 8 times more opportunities to use adaptive coping strategies compared to PLWHA who gave spiritual meaning to their illness experience in a negative way. These findings can provide evidence for nurses to facilitate and guide PLWHA in discovering the spiritual meaning of the experiences of illness and developing strategies for using positive coping in order to enhance their positive attitudes and behaviors.

Keywords—Coping Strategies; People Living With Hiv/Aids; Spiritually Meaning Of The Experience Of Illness

I. INTRODUCTION

The spiritual meaning of the experience of illness or also called *hikmah* is the perception of the individual in making meaning of the illness that he experienced. The client's perception of his illness can accelerate the healing process but can also worsen the condition of the illness [1]. Illness perception can affect coping strategies used in responding to Human Immunodeficiency Virus (HIV)-related stress, and the clinical status of patients [2]. People living with HIV/AIDS (PLWHA) can interpret the illness positively or negatively. If the illness is interpreted positively then positive things will be done, including positive coping to overcome the problems experienced, and vice versa [3]. But until now there has been no evidence that shows the relationship between spiritual meaning (*hikmah*) of the experience of illness and coping strategies used by PLWHA in overcoming their illness.

HIV has become a major global health problem, and so far it has caused more than 32 million deaths. With increased access to effective HIV prevention, diagnosis, treatment and care since the last decade, the HIV infection has become a chronic health condition that can be managed, slowing the progression of AIDS, and allowing PLWHA to live longer and healthier lives [4, 5]. In this context, facilitating PLWHA to be able to take on a positive spiritual meaning

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for their ill experiences and to guide the development of adaptive coping with PLWHA is a challenge for nurses so PLWHA can maintain and improve their quality of life.

According to the World Health Organization (WHO), around 37.9 million people are living with HIV; by the end of 2018 there were 1.7 million new infections globally. Africa is the most affected region, with 25.7 million people living with HIV and also contributing nearly two-thirds of the total new HIV infections in the world [4]. In Asia-Pacific there are an estimated 310,000 new HIV infections, bringing the total number of people living with HIV in the region to 5.9 million by 2018 [6]. Around 200,000 people have died of AIDS-related diseases in the region. There has been a 24% reduction in deaths since 2010, but in several countries including Afghanistan, Bangladesh, Indonesia, Pakistan and the Philippines AIDS-related deaths have increased [4].

According to the HIV/AIDS Development Report and Sexually Transmitted Diseases in Indonesia in the Second Quarter of 2018, the number of people infected with HIV up to June 2018 was reported to be 10,830, where the highest percentage of HIV infections was experienced by the age group 25-49 years (70.3%) and ages 20-24 years (15.9%). The number of people infected with AIDS up to June 2018 reported as many as 1,864 people, with the highest percentage in the 30-39 years age group (33.5%) and 20-29 years old (29.3%), where the proportion of HIV and AIDS infections was both AIDS in men and women are equal to 1:1 [7].

Nursalam in 2018 stated the problems experienced by PLWHA were not only in the scope of physical health, but also had an impact on their social, psychological, environmental, and spiritual life [8]. PLWHA often get negative views in the community, where they are considered to have a negative background and association. The Indonesian Ministry of Health identifies various problems experienced by PLWHA from the surrounding environment, namely avoidance, angry experiences, rejection, being considered social diseases, and behavior to hide their diseases so that they are not isolated from the surrounding community. The negative stigma and discrimination experienced by PLWHA can harm their self-acceptance and make it more difficult for them to cope with their illness [9].

In 2018 the WHO explained that when individuals were first declared infected with HIV, most showed changes in their psychosocial characteristics such as stress, depression, feeling lack of social support, and changes in behavior. Stress can worsen an individual, increase the replication of the HIV virus [10]. Joerban in 2015 revealed that almost 99% of people with HIV/AIDS experience stress or severe depression when they find out they have AIDS. Significant life stressors have also been associated with poor physical and mental health in HIV. Once exposed to an adverse life event, an individual is at risk of being exposed to future stressors, creating a life-course of chronic stress that takes a long-range toll on physical health via sustained activation of the stress response which is pathogenic in nature [11]. In the context of HIV, the immune system is compromised and, consequently, stress exacerbates the immunosuppressant response leading to poorer health outcomes in PLWHA. Indeed, work with PLWHA has found substantial evidence that stress negatively affects HIV disease progression [12]. For example, in a recent 4-year longitudinal study, norepinephrine, a neurohormone related to stress, was associated with a greater rate of increase in viral load and decrease in CD4 [12]. In a sample of PLWHA, individuals with depression were 3.5 times more likely to have reported experiencing stress [13]. Life stress has also been shown to be a risk factor for drug use [14] [15], including in PLWHA [16]. For this reason, individuals must be able to reduce their stress levels by adapting strategies so the virus does not continuously replicate [17].

The strategy to maintain physical and emotional conditions is a coping or a method used by PLWHA to master, reduce, or tolerate demands in the form of unpleasant conditions from physiological and emotional stimuli experienced in situations considered dangerous or that threaten the welfare of PLWHA [18]. There are various views about coping strategies. Lazarus and Folkman in 1984 generally differentiated coping strategies into two classifications, namely coping strategies focusing on problems and those focusing on emotions [19]. Stroppa, on the other hand, said in 2008 that coping can also be sourced from a religious/spiritual aspect called religious/spiritual coping (RSC) [20]. In 1986

Schwartz divided coping strategies into adaptive and maladaptive coping [21]. Many PLWHA use a maladaptive coping strategy, which has implications for decreasing health and quality of life. Temoshok explained in 2008 that using maladaptive coping strategies can accelerate the development of the disease itself [22]. Conversely, the use of positive coping strategies can produce good health in which one of its uses is through a spiritual approach.

The spiritual meaning of the experience of illness varies from client to client. PLWHA can interpret various experiences of illness. Rahmawati and Muljohardjono said the meaning of illness for someone is subjective, depending on one's experience and knowledge before illness [3]. Whereas Travelbee said in 1971 the spiritual meaning of the experience of illness was influenced by one's personal spiritual/religious attitudes and behaviors. Positive meaning occurs when someone accepts his illness as destiny, resignation, patience and tries to recover, whereas negative meaning occurs if he considers himself weak and helpless without making any effort, loses meaning to recover and tends to isolate himself from social activities and even lose life spirit.

The meaning of illness is the most important part in the process of experienced by each individual, because the interpretation of illness that can provide a perspective for each subject about the conditions they experienced [23]. This study aims to investigate the relationship between spiritual meaning (*hikmah*) of the experience of illness and coping strategies used by PLWHA in overcoming their illness in Kemayoran District Hospital, Jakarta, Indonesia.

Based on his literature review, in 2017 Lie Ku concluded that the majority of existing definitions of spirituality were inconsistent and contaminated by the concept of mental health [24]. Spiritual is a two-dimensional concept, with horizontal and vertical dimensions. In 2014, Puchalski, Vitillo, Hull, and Reller interpreted spirituality as an aspect of humanity that refers to the way individuals seek and express the meaning and purpose of life and how they experience their connection with the moment, with themselves, with others, with nature, and with something significant or sacred [25].

The horizontal dimension is the relationship with oneself, others, and the environment, while the vertical dimension is a relationship with God or the Highest [26]. According to Burkhardt Spiritual aspects consist of how a person finds meaning in life's purpose, realizes the ability to use resources and strengths in oneself, and has a feeling of attachment to oneself and with the Highest. The spiritual meaning of the experience of illness is an individual's perception of the meaning of the illness that he experiences in a spiritual context. Meanwhile, in 2011 the Royal College of Nursing (RCN) stated that spirituality is about hope and strength; trust; meaning and purpose; forgiveness; beliefs and beliefs in oneself, others, and for some this includes belief in a god or a higher power; community values; love and relationships; morality; and creativity and self-expression [24] [27].

The spiritual meaning of the experience of illness by PLWHA is their ability to perceive and find spiritual meaning or *hikmah* for the illness they experienced. In the context of the experience of illness, the *hikmah* is an attitude of taking and using a deep meaning over the events experienced by illness. Sabarhadi [28] [29] and Bahraen [30] identified the spiritual meaning of an illness experienced by humans such as being interpreted as a test, as a substitute for sin and error, a sickness that will elevate and increase goodness; illness is the reason to achieve a higher position/degrees, sickness is proof that God wants goodness to HIS servants, sickness brings people to *muhasabah* (self-introspection), sickness is the cause of the return of my servants to His God, sickness as events that will improve the heart, and illness as a reminder of servants towards favors healthy.

Meanwhile, in 2015 Fillah stated that illness must be interpreted as dhikrullah - because those who are sick will more often mention the name of God when compared to being healthy; illness is forgiveness, sins will be easily remembered when it comes to illness, so oral guidance to ask forgiveness; illness is monotheism - when in extreme illness, the sentence thoyyibat will be said; sickness is muhasabah - where sick people will have more time to reflect on themselves in silence, calculating their provisions; sickness is jihad - meaning that sick people must not give up losing, are required to continue to strive, fight for their health; sickness is science - because when sick, people will check

themselves, consult and eventually take care of themselves for the next time there is knowledge to not easily experience illness; illness is advice - for the sick it will be a reminder to keep themselves from getting sick and stay healthy, and for the healthy to comfort the sick individual to be patient; illness is silaturrahim - family and friends who rarely meet can visit, therefore also illness is the glue of ukhuwah; illness is the introduction of sin and the granting of prayer; sickness is one of the conditions that makes it difficult for Satan to engage in immorality; the illness makes one laugh a little and cry a lot; it improves the quality of worship; illness improves morals - that is, eliminating pride, subduing greed, making a polite, gentle and tawadhu person; and ultimately illness brings us to always remember death - remembering death and preparing to multiply good deeds are a booster of the degree of devotion [30].

The measurement of spiritual meaning is a method used to see how a person interprets his illness experience spiritually. By referring to the concept of Fillah, spiritual meaning (*hikmah*) of the experience of illness is categorized as positive and negative spiritual meaning [30].

In 2006 Hawari defined coping as a process in which a person tries to regulate the difference received between wants (demands) and income (resources) which are valued in an event or a stressful situation [8]. In 2009 Taylor stated coping is a general tendency used by individuals to deal with stressful events in certain ways [8]. A coping mechanism is a mechanism used by individuals to deal with accepted changes. If the coping mechanism is successful, then the person will be able to adapt to these changes.

There are types of coping strategies in literature. Lazarus and Folkman in 1984 generally distinguished forms of coping strategies into coping strategies focused on problems and coping strategies focused on emotions [31]. In 2008 Stroppa added that religious people often present a greater capacity to overcome bad conditions in their lives through the use of religious/spiritual coping (RSC). When the patient uses religious elements for this purpose, he uses religious coping, and this is an important source of coping [20].

Coping Strategies Focusing on Problems is an action directed at solving problems. Someone will tend to use this behavior if they assess the problem they are facing can still be controlled and can be solved. Coping behavior that is problem-centered tends to be done when the individual feels that something constructive can be done about the situation or he believes that the resources owned can change the situation. The coping strategies focused on the problem are 1) Planful Problem Solving, which reacts by making certain efforts aimed at changing the situation, followed by an analytical approach in solving problems; 2) Confrontative Coping, which is reacting to change circumstances that can describe the level of risk that must be taken; 3) Seeking Social Support, which is reacting by looking for support from outside parties, whether in the form of information, real assistance, or emotional support.

Coping Strategy Focusing on Emotions is making efforts aimed at modifying emotional functions without making efforts to directly change the stressors. Emotional-centered coping behavior tends to be done if the individual feels unable to change the stressful situation and can only accept the situation because the resources possessed cannot cope with the situation. The coping strategies focused on emotions are 1) Positive reappraisal (giving a positive assessment) is to react by creating positive meaning that aims to develop themselves including involving themselves in religious matters; 2) Accepting responsibility (emphasis on responsibility) that is reacting by raising awareness of the role of the self in the problems faced, and trying to put things as they should; 3) Self-controlling (reacting) by reacting by regulating both feelings and actions; 4) Distancing (keeping a distance) so as not to be shackled by problems, and 5) Escape avoidance (avoiding oneself) that is avoiding the problem at hand.

Coping Strategies Focusing on Spiritual—According to Wong and Gorsuch, spiritual coping is an individual's way of using his beliefs in managing stress and problems in his life [24]. Meanwhile, according to Pargament, spiritual coping is an effort to understand and overcome the sources of stress in life through various ways of strengthening individual relationships with God [24]. This is one strategy to minimize or overcome the stress that arises by performing worship or getting closer to Allah SWT. Pargament who is a pioneer of spiritual coping identifies spiritual coping strategies into

3, namely: 1) Collaborative, a coping strategy that involves God and the individual in collaboration to solve problems experienced by individuals; 2) Self-directing, which means an individual believes that he has been given the ability by God to solve the problems he faces; 3) Deferring, that is, individuals depend entirely on God in giving cues to solve the problem.

II. METHODS

The design of this study is descriptive-analytic with a cross-sectional approach to the population of PLWHA visiting Kemayoran District Hospital in Jakarta. Through purposive sampling using Slovin formula a sample of 30 people was obtained using these criteria: willing to be respondents, able to listen and communicate well, and adults or older.

Data collection was performed using two questionnaires, namely coping strategies and spiritual meaning of the experience of illness. To measure the coping strategy The Way of Coping Questionnaire (WCQ) was used which was revised by Folkman in 1986. WCQ contains 15 positive statements consisting of coping strategies focused on the problem (statements 1 to 5), coping focuses on emotions (statements 6 to 10), and spiritual-focused coping (statements 11-15), with 4 choices of answers that are always, often, rarely, and never. Scores for each respondent were categorized as maladaptive coping (≤ 47) and adaptive coping (> 47).

Meanwhile, to assess the spiritual meaning we used the Questionnaire Spiritual Meaning of Illness Experience (QSMI) which refers to the concept of Fillah (2015). QSMI consists of 10 positive statements with 4 answer choices, namely always, often, rarely, and never. Spiritual interpretation scores on illness experiences are categorized as negative (≤ 30) and positive (> 30). Both instruments have been tested and each shows an alpha value (0.961) and is suitable for use.

A univariate data analysis was performed to see the description of respondents' characteristics including age, sex, duration of illness, and occupation in the form of proportions (%). A bivariate analysis was conducted to determine the relationship between the spiritual meaning of the experience of illness and PLWHA coping strategies, using the Chi-square test at a 95% confidence level. This research was conducted with respect to subject rights, justice, confidentiality and beneficence.

III. RESULTS

The results of the univariate analysis are presented in Table 1 which shows the frequency distribution based on characteristics of age, sex, duration of illness, and occupation. The results of the bivariate analysis are presented in Table 2 which shows the relationship between the spiritual meaning of the experience of illness and coping strategies in PLWHA.

Table 1. Frequency Distribution Based on the Characteristics of Age, Gender, Working Status, Duration of Illness in PLWHA at Kemayoran District Hospital, Jakarta (n = 30)

Variable	Frequency	Percentage (%)
Age		
≤ 30 years old	9	30
> 30 years old	21	70
Sex		
Male	26	86.7
Female	4	13.3
Period of illness		
≤ 2 year	13	43.3
> 2 year	17	56.7

Variable	Frequency	Percentage (%)
Working status		
Employed	10	33.3
Unemployed	20	66.7

Table 1 shows most respondents were aged over 30, 21 people (70%). 26 were male (86.7%), the illness lasting for more than 2 years was experienced by as many as 17 people (56.7%), and the majority of respondents were unemployed, as many as 20 people (66.7%) .

Table 2. The Relationship between the Meaning of Spiritual Experience of Illness and Coping Strategies in PLWHA at Kemayoran District Hospital, Jakarta (n = 30)

Meaning of Spiritual Experience of Illness	Coping Strategy				Total		OR (95% CI)	P-value
	Maladaptive		Adaptive					
	n	%	n	%	n	%		
Negative	10	76.9	3	23.1	13	100	8,000	
Positive	5	29.4	12	70.6	17	100	(1.522 – 42042)	0.010
Amount	15	100	15	100	30	100		

Table 2 shows that the results of the relationship between the spiritual meaning of the experience of illness and coping strategies in PLWHA in Kemayoran District Hospital, Jakarta, Indonesia. 17 respondents have positive spiritual meaning, 12 respondents (70.6%) have a positive spiritual meaning and 5 respondents (29.4%) have a negative spiritual meaning. The results of the Chi-square statistical test of the relationship between the spiritual meaning of the experience of illness and coping strategies in PLWHA at the Kemayoran District Hospital, Jakarta, Indonesia obtained $p= 0.010$ or smaller than alpha (0.05), so it can be concluded that there is a significant relationship between the spiritual meaning of the experience of illness and the use of coping strategies in PLWHA at Kemayoran District Hospital, Jakarta, Indonesia. The test results obtained OR value= 8.000 meaning that PLWHA with the spiritual meaning of positive experience have 8 times the opportunity to use adaptive coping strategies compared to PLWHA who have a negative meaning of the spiritual experience.

IV. DISCUSSION

The results of this study are consistent with the Nobre et al.'s study in 2017 which concluded that overall, the majority of PLWHA were male (76.3%), and had been diagnosed with HIV for an average of 10.6 years. Another study concluded that the majority of PLWHA were 63% male, unemployed, and had lived with HIV for a longer period [22].

This research has shown that PLWHA who interpret spiritually their experiences of illness with positive perceptions encourage adaptive coping such as behaving in a manner that is ethical, conducting self-introspection, fostering a fighting spirit to regain their health status, considering illness as an expression of God's love and affection for him, feeling the experience of his illness as an explorer of sin and mistakes in the past, more reminding himself to God, preventing him from doing acts that God forbid, making him closer to God, and increasing his good deeds as a provision to death.

The results of this study are in line with Chen et al.'s from 2019 who stated that the strategy to overcome the problem through confrontation (hostility/contradiction, is one type of coping focused on the problem), a higher score is obtained by those who are first diagnosed with HIV when younger than 50. Those who have lived with HIV for a longer time are more likely to adopt a coping strategy of acceptance-resignation in response to HIV/AIDS [30].

Chrisnawati (2018) concluded that there is a relationship between the use of coping strategies in her self-acceptance where the higher the coping strategies that focus on the problem and emotions used, the higher the self-acceptance of

her illness. Likewise, in 2019 Ramdhani proved that the higher the maladaptive religious coping implemented by PLWHA, the lower the quality of life, and could even worsen a person's quality of life. Vice versa, the more individuals reduce the use of maladaptive religious coping, the better quality of life the individual can achieve [32]. Another study concluded that negative perceptions were associated with dysfunctional coping strategies (such as passive coping and alcohol use) in dealing with HIV-related stressors [2].

Various literature in the US has documented the importance of spirituality in the psychological health of HIV-positive people. Research also shows that PLWHA who report greater involvement in spiritual activities report lower emotional pressure, lower depression, greater optimism, and are better adapted psychologically. Another study of PLWHA in the US has proven that spirituality is very strong and positively related to the feeling that life has improved. People who report an increase in spirituality after their HIV diagnosis have also been shown to have significantly higher CD4 cell counts, and significantly better suppress viral load, after controlling for other factors [33].

V. CONCLUSION

Most respondents were more than 30 years old, as many as 70%, with male dominating by 86.7%, diagnosed with HIV for a long time, more than 2 years at 56.7%, and as much as 66.7% of the respondents were not working,

There is a significant relationship between the spiritual meaning of the experience of illness and coping strategy of PLWHA, and PLWHA who gave spiritual meaning to their illness experience in a positive way had 8 times more opportunities to use adaptive coping strategies compared to PLWHA who gave spiritual meaning to their illness experience in a negative way.

These findings can provide evidence for nurses to facilitate and guide PLWHA in discovering the spiritual meaning of the experiences of illness and developing strategies for using positive coping in order to enhance their positive attitudes and behaviors.

CONFLICT OF INTEREST

This research is free from conflict of interest.

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