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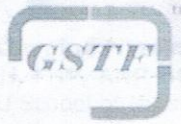
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# Caring for Self: Perceived by Persons Living with HIV Infection in Bandung, Indonesia



Kusman Ibrahim, Praneed Songwathana, and Umaporn Boonyasopun

**Abstract.** The continuing increase of persons living with HIV infection (PLWH) in Indonesia is impacting on society. This is a part of focused ethnographic study aims to explore and describe the caring perceptions among Muslim PLWH in Bandung, Indonesia. Twelve PLWH were recruited purposively participate in this study. Data collection included participant observation, interviews and field notes during the eight months period. The Leininger's ethn nursing phases of qualitative data analysis were used as the guideline in analyzing process. Four major themes emerged: (1) accepting the reality of being an HIV-infected person while submitting self to Allah (God); (2) striving to maintain health by performing optimum efforts and supplication; (3) gaining the blessing of God by doing good deeds and worship; and (4) building brotherhood and networking to share, support, and help each other. Findings indicated that the patient's perceptions of caring were related to socio-cultural context especially Muslim teaching and cultural beliefs. Health care providers, particularly nurses, could take this knowledge to design a culturally congruent community based care for PLWH and their family members.

**Keywords;** *Caring, Persons Living with HIV Infection, Indonesia*

## I. INTRODUCTION

There were an estimated 35 million people living with Human Immunodeficiency Virus (HIV) globally and 19 millions of them do not know that they have the virus<sup>1</sup>. The HIV pandemic is still a major problem and poses continual challenges to many countries. Indonesia is one among 15 countries that reported over 75% of the 2.1 million new infection that occurred in 2013. Indonesia has been facing increasing numbers of PLWH since the first case was identified in 1987. The country has been noted as having the fastest growing HIV epidemic in Asia<sup>2</sup>. Up to September 2014, the number of people with HIV were reported 150,296, and 55,779 persons have been in the stage of AIDS<sup>3</sup>. Bandung is a city that reported as the highest number of PLWH in Indonesia, which was 3,267 cases cumulatively up to September 2014<sup>4</sup>.

Recent advancement in HIV/AIDS treatment has transformed AIDS from a fatal condition to a chronic manageable disease<sup>5</sup>. As the other chronic illnesses, long-

term care for PLWH become a major concern among health care providers. Self-care in the context of chronic illness is important strategy to successfully manage symptoms progression and discomfort along with the disease course. Self-care has been found to correlate with values, beliefs, and cultural traditions of patient population<sup>6</sup>. The significance of self-care is underlined in the definition of chronic illness as "a condition not cured by medical intervention and requiring periodic monitoring and supportive care to reduce the degree of illness and to maximize the person's functioning and responsibility for self-care"<sup>7</sup>. Self-care practice may include a range of activities carried out by individuals to improve health, prevent illness, evaluate symptoms, and restore health<sup>8</sup>.

"Care" in the Nursing perspective is culturally embedded in the daily practice of people, both at individual and community level<sup>9</sup>. Expression of care is influenced by cultural background, values, beliefs, as well as a life ways of people. It is imperative for healthcare providers to understand meanings of care in a particular context of specific sub-cultural groups of care recipients, in order to provide cultural congruence of care. Healthcare providers, including nurses, are expected to provide high quality of care to the patients regardless of their illness or disease<sup>10</sup>. A number of studies have been focused on the impact of HIV and AIDS experienced by HIV-infected persons and caring for those patients experienced by nurses. Little is known about how persons living with HIV perceive care for themselves in the Indonesian cultural context.

## II. METHODS

### A. Aims

The aim of this study is to explicate caring for self as described by Persons Living with HIV Infection in Bandung, Indonesia. The findings of the study may provide a practical knowledge to develop a culturally

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congruent type of care and facilitate the support for people living with HIV infection.

### B. Design

A focused ethnographic study was utilized in this study to discover, describe, and systematically analyze the emic care perceptions within a specific cultural and environmental context. This approach enabled the researcher to develop insight into phenomenon regarding caring perceptions among persons living with HIV infection in the Bandung, Indonesia.

### C. Data Collection and Analysis

To gain trust of informants and allow contextual understanding of the phenomenon under investigation, the researcher immersed in the naturalistic setting. Being the primary instrument for this study required reflexivity from the researcher. It means the researcher deliberately using “self” in data collection and analysis while being aware of the ways in which “self” affects both the research process and its outcomes<sup>11</sup>. Thus, the researcher had to keep his preconceptions and values aside throughout the research process, while intimately interacting with informants and the data.

The participants were informed about the study objective and their right to withdraw from the study. Twelve PLWH were selected purposively from an urban and sub-urban area at Bandung District based on several criteria including (1) knowing their HIV positive status for at least six months, (2) being an adult, (3) having experience in receiving care from health care providers, and (4) willing to participate in the study. The Non-Government Organizations’ staffs working for HIV/AIDS served as gatekeepers, facilitating access to participants.

Data were collected through participant observation and interview. The researcher interviewed all informants in their home, which each interview being audiotaped and lasting 45 to 60 minutes. The initial question was usually a broad descriptive question such as “How is your daily life going?” Structure and contrast questions were asked to explore more deeply toward the caring for themselves, included beliefs and values perceived by the informants. During the interview, the researcher encouraged the informants to clarify and elaborate the details of their experience by using probes or focused questions such as “What does it mean to you?”, or “What does make you think like that?” The researcher kept interviewing informants until reaching the stage when no new information emerged by extending the interviews. In order to gain a full and complete perspective of what was occurring during participant observation and interview process, a tape recorder, filed note, and camera were used to capture data. The information was considered as saturated when no new information could be elucidated by informants. In another word, when sufficient data had

been recorded, the saturation stage was reached. Trustworthiness of this study was ensured by the process of credibility, confirmability, and transferability as suggested by Lincoln and Guba<sup>12</sup>. The thick descriptions of the findings, the peer review of three members in the research team and playback method from participants were mainly used in order to evaluate the validity and trustworthiness of the data analysis results.

Data were analyzed on a daily basis. Initially data were written or transcribed in Indonesian language. Informants who spoke Sundanese (local language) were recorded and transcribed into Indonesian language. Furthermore, the *researcher* translated the data into English and asked an Indonesian English-teacher qualified to verify the accuracy of meaning and context of certain terms or phrases. The process of data analysis in this study involved four steps as recommended by Leininger<sup>9</sup> included: (1) collecting, describing, and documenting raw data, (2) identification and categorization of descriptors and components, (3) identification of patterns and contextual analysis, (4) formulation themes and research findings.

### D. Study Context

This study was conducted at a sub-urban area of Bandung City. Bandung’s population is mostly Sundanese. Sundanese refers to both the name of an ethnic group, which is the second largest ethnic group in Indonesia, and the local language spoken by the ethnic group. Islam has become an essential part of life among the majority of Bandung people. It influences all aspects of life including respond toward diseases, illness, health, and well-being. Bandung has experienced a more rapid development than other parts of Indonesia. It has become a popular weekend destination for people from outside the city due to the cool climate and beauty of the landscape. Bandung’s economy is mainly based upon farming, retailing, services, tourism, and manufacturing. HIV has become a major public health concern in the city, due to the rapid increase of the epidemic and the cultural “silence” a result from the stigma which associates the illness with immoral behaviors according the religious beliefs.

Informants consisted of six males and six females with mean age of 30 years old (SD = 6.9). All of them are Muslim. Eight of them completed senior high school, two finished junior high school, one had a bachelor degree, and one came from the primary school. Eleven of them were married. All but one was having insufficient income to meet daily needs. Six of them were former IDU, whereas six others were wives infected by husbands who engaged with risks behavior either IDU or visited prostitute. Living with HIV infection has exposed the informants to various health problems such as losing body weight, changing physical appearances, chronic coughing, weakness, and other HIV co-morbidities.

Emotional disturbances, economical hardships, and social powerlessness have put this group at a vulnerable level toward health care service which needed a specific approach to encourage them come to health care facilities. However, for some PLWH including those who were involved in this study, the complex problems of living with the illness has drawn significant meanings to reconstruct and reshape their interpretation toward experience of caring for self in their cultural context.

#### E. Ethical Consideration

Ethical approval was given by the Institutional Research Board, Faculty of Nursing, Prince of Songkla University. Permission for data collection from the local authorities was also obtained. A complete explanation and written description about the objective of the study, the research method, potential risks and benefits to participants were given to the participants. They were invited to ask questions and to decline or accept participation in this study and could withdraw from the study at any time they would wish. Either verbal or written informed consent was offered to each informant before beginning with the interviews.

### III. FINDINGS

Four themes related to meanings of caring for self addressed by PLWH emerged from the data. Each theme, supported by patterns and descriptors, is presented in the following section.

*Theme 1: "Pasrah", accepting the reality of being HIV-infected person while submitting self to Allah*

All key informants understood that the current situation of being an HIV-infected person is a part of real life. They knew that they could not escape or run away from reality. Accepting as it is and submitting self to Allah while hoping for a better life, would help them to cope with prolong suffering from HIV illness. Key informants who had engaged with particular risky behaviors perceived it as a consequence. Whereas those who were infected by husband perceived it as a risk of their ignorance in accepting a husband without being curious about his detailed background related to behavioral risks which might lead to HIV. However, all of them perceived that being an HIV infected person presently was their destiny of Allah. Every single individual would have his/her own destiny. This is supported by the following statements:

*"Now, I couldn't do anything much, except of accepting the reality as it is. This is my destiny. I don't know how much longer my age is still remaining. Only one thing, I care for my self by means of 'pasrah' or submitting self to Allah and hope everything will be better in the future" (K9)*

*"As a human being, sometimes my emotion is labile. Yet if I keep thinking my condition, it would bother me so much which lead me to relapse on using the drugs. That is way, just let everything go naturally. This is my way of life set by Allah. It has to be like this. I accept this reality of being an HIV-infected person and submit everything to the will of Allah. This is a meaning of caring to me" (K6)*

*Theme 2: Striving to maintain health by performing optimum "ikhtiar" (efforts) and "do'a" (supplication)*

Nine key informants expressed their insight about caring for self as performing optimum efforts to maintain health. Issues of stigma and discriminations and deterioration of their health along with HIV illness progression have posed a huge challenge to the informants, being more aware now and valuing health and life. Regret, frustration, despair, and hopeless following the HIV diagnosis should not be present continuously, as that would in itself even lead to life termination. The informants believed God has already set a plan for every single creation. Health, according to the informants, was an essential capital to keep life going forward meaningfully. Therefore, they might devote various means to get and maintain healthy. As one key informant said:

*"Although living with this illness is so terrible, I believed that Allah has the best plan for me. I must continue striving for life by maintaining good health. To me, care means performing 'ikhtiar' (optimum effort) to keep myself healthy. I would do whatever ways to be healthy as long as it is plausible and relevant to my beliefs" (K8)*

*Theme 3: Gaining the blessing of God by doing good deeds and worship*

Seven key informants acknowledged their previous behaviors as a mistake that brought them to get HIV infection. The current situation of being an HIV-infected person was perceived by the informants as the time for doing good actions to compensate the previous mistakes. Some of them learned that many of their friends died without having much time to do atonement. In this case, they thanked to Allah for giving them time to return back into the right track as religiously and socially ordered. The informants believed that by doing good actions, Allah would forgive their mistakes and purify their sins. Thus, they may enter paradise in the hereafter. Doing good actions were also perceived as a form of their responsibility to worship Allah. This is supported by the following statement:

*"Thank Allah for allowing me to remain alive though I have done many mistakes in the past. So, to me*

*caring means I have to do good things to compensate my previous mistakes. Now, I am trying to normalize my life and living in accord with community's norms. I believe that God is merciful, so I intend to gain His blessing by returning to the right way and doing goods" (K1)*

*"... So, to me, caring means taking responsibility to do good things by sharing my experience in living with HIV, in order other people are able to prevent it and understand how to treat PLWH. It is also as a proof of my worship to Allah" (K11)*

#### *Theme 4: Building "persaudaraan" (brotherhood) and networking to share, support, and help each other*

Living with HIV infection including the various issues attached to the illness has motivated the informants to find other HIV-infected persons to share, support, and empower each other. The commonality of problems faced by PLWH allowed them to share their feelings and cultivate "persaudaraan" or the sense of brotherhood among HIV survivors. With the assistance of the NGOs working for HIV/AIDS, some PLWH organized self-help groups which facilitated them to gather and empower themselves by sharing knowledge and experience in dealing with particular issues related to living with HIV infection. By joining the group, the informants might take advantage by learning from other members who have the same experience. Thus they develop cohesiveness and brotherhood among them as a manifestation of caring which was in line with their religious beliefs. One key informant expressed her impression of another member who genuinely helped her when passing the initial stage of the stressful event of being diagnosed with HIV She said:

*"I am very thankful to a friend who advised me to attend the PLWH self-help group when the first time facing HIV diagnosis. This has opened my eyes that there are other persons as well who suffering from this illness, not only me as I presumed before. In the group, we learned, shared, and support each other, we feel close and alike "saudara" (brother) due to feeling of "senasib sepenanggungan" (sense of having similar fate). I think this can imply as the meaning of caring for us which also encouraged by Islamic religion." (K8)*

One key informant, who was a founder of a self-help group for PLWH and IDUs, added a comment about the importance of developing a sense of "persaudaraan" among PLWH as meaning to care for themselves This was because he and his friends encountered many issues such as fear of exposing their status to their family as well as people in the community people in the community. Other problems were barriers in accessing health care services, and lack of awareness among IDUs about checking their HIV status and taking measures to

prevent HIV transmission. These triggered him to establish the self-help group. He found that this was very useful for him and his friends to develop caring and "jejaring" or networking each other. He expressed this:

*"We are HIV-infected persons usually have many things in common the need to be responded to appropriately. We deal with fear of exposing our HIV status to our family and people because no all of them are ready to accept HIV-infected person, barriers in accessing health care services due to negative attitudes among health care providers toward PLWH and IDUs, and many of our friends were unaware about HIV which prevented them from getting tests. That way I established the group to develop "persaudaraan" and "jejaring" among us because if we don't care for ourselves, no one would care for us automatically. So, in my opinion, it can be a meaning of caring for ourselves." (K12)*

#### IV. DISCUSSION

It was shown that the religious belief has sharpened the informants in construction the meanings of caring for self. The first three themes were more likely reflecting a specific or diverse meanings of caring derived from Islamic cultural beliefs, while the last theme reflects the universal meaning of caring which could be found in other cultures. The findings are supported by previous studies that highlighted the influence of social, cultural and religious beliefs on HIV and caring for people living with HIV infection<sup>6,13-16</sup>.

Having HIV infection was viewed as a reality that had happened and could not be avoided, unless being accepted with care. Care, in the informants' view covered utilizing all beliefs, values, and efforts to maintain health and well-being while being with HIV infection. The theme "accepting the reality of having HIV infection while 'pasrah' (submitting self) to God" reflects the belief of God as the supreme power, which all creatures depending on Him. Belief in God is a central tenet of Islam that influences all aspects of life as a Muslim<sup>17-18</sup>. Previous studies documented the influence of faith in believing in God in dealing with HIV/AIDS impact<sup>19-20</sup>.

Although the reality of being an HIV-infected person could not be avoided, it should not lead to frustration or hopeless. The theme "striving to maintain health by performing optimally "ikhtiar" (effort) and "do'a" (supplication)" indicates the Islamic belief related to attaining the goal in a Muslim's life. In this context, health is the goal. To achieve the goal, two main things must be performed; effort and supplication. Effort means here utilizing all available renounces and the ability to achieve something, while supplication refers to invoke something to God with humility which is insisting in



request and continuously in worship and secrecy<sup>21</sup>. Fadlullah<sup>22</sup> asserted that supplication is the living expression of a human being's everlasting need for God. Believing in God becomes meaningless if it does not involve the acknowledgment of His supernatural and His absolute and endless power against the helplessness and weakness of the human being who cannot do himself any harm or good but through the help of God. In this context caring meant utilizing all of the endeavors while supplication to God for the best outcomes as acknowledgment of human weakness without any help from God.

Since God, the Creator and Lord of all beings, is the central belief in Islam, gaining His blessing was viewed as essential in Muslim life. The theme of "gaining blessing of God by doing "kebaikan" (good deeds) and worship" mirrored the firm belief of the informants in God. Kutty<sup>23</sup> stated that blessing in Islam means mercy of God which indicates His love and eternal salvation for the blessed ones. Islam is essentially surrendering self totally to God by dedicating everything to Him. Thus, every single utterance or deed that is begun in the Name of Allah and with the intention of seeking the pleasure of Allah is considered blessed; likewise, each and every matter that is not begun in the Name of Allah is considered disfigured. Doing good deeds and worship God is a mean to gain blessing of God. Some examples of doing good deeds that are recommended by Islamic teaching were patience, control over passions and desires, control over bad temper, prayer regularly, visiting the mosque, reading the Qur'an, family gathering, concern for the community matters, etc. True and sincere worship creates humbleness and it always leads to more acts of goodness and virtues<sup>24</sup>.

PLWH show commonalities in terms of having similar issues related to deal with HIV/AIDS and its impacts. "Building "persaudaraan" (brotherhood) and "jejaring" (networking) to share, support, and help each other" indicated they care for each other, which reflects the implementation of their cultural and religious beliefs. In Islam, all people constitute one brotherhood. No one is beyond the borders of this brotherhood. Islam makes it clear that wealth, position, lineage or social status are not valid reasons for feeling arrogant or superior<sup>25</sup>. Feeling of having commonalities which are supported by religious beliefs has driven PLWH to cultivate a culture of brotherhood which allowed them to share, help, and support each other.

## V. CONCLUSION AND RECOMENDATIONS

This study presented "caring for self" constructed among PLWH in Bandung community which reflected universality and diversity of cultural beliefs and values. The results might be very helpful in developing

community based care related to religious and cultural belief, as well as self help groups in dealing with feelings and living positively with HIV. The findings of the study would suggest the health care providers, particularly nurses, to recognize and acknowledge the culturally-bound meaning of caring in order to provide culturally congruent care for PLWH. Further studies are required such as culture of care among other population in various geographic areas to enrich transcultural care knowledge throughout Indonesia, identify the process and outcomes of caring to strengthen the caring practices among PLWH.

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