Submitting self to *Allah*: Care perception of persons living with HIV infection in Muslim community of Bandung, Indonesia

Kusman Ibrahim[1], Assoc. Prof. Dr. Praneed Songwathana[2], Assist. Prof. Dr. Umaporn Boonyasopun[3]

1. PhD Candidate in Nursing, Faculty of Nursing, Prince of Songkla University, Hat Yai, Thailand/ Lecturer, Faculty of Nursing, Padjadjaran University, Bandung, West Java, Indonesia
   Email: k.ibrahim@unpad.ac.id
2. Department of Surgical Nursing, Faculty of Nursing, Prince of Songkla University, Hat Yai, Songkhla, Thailand
3. Department of Public Health Nursing, Faculty of Nursing, Prince of Songkla University, Hat Yai, Songkhla, Thailand

Abstract

This focused ethnography aims to explore and describe the conceptions of care among people living with HIV infection (PLWH) in the Muslim community of Bandung, Indonesia. Twelve key informants and eight general informants were selected to participate in this study. Data collection included participant observation and interviewing. The Leininger's ethnonursing phases of qualitative data analysis were used as the guideline in analyzing the data. Four major themes emerged from the data: accepting destiny of being an HIV infected person while submitting self to *Allah* (God) hoping for a better life, performing a maximum effort to maintain health, doing good deeds to compensate previous mistakes related to HIV, and caring as part of parenting responsibility. Health care providers, particularly nurses, could take benefits from this knowledge to design a culturally congruent care for PLWH as well as for their family.

Keywords: submitting self, Allah, care, persons living with HIV, Muslim, Indonesia

Background and significance of the problem

In 2007, over 6,800 people become HIV infected and over 5,700 people die from AIDS every day due to inadequate access to prevention, care, and treatment services (UNAIDS & WHO, 2007). The HIV pandemic is still a major problem and poses continual challenges to every country, regardless regions and/or cultural beliefs (Fauci, 1999). Indonesia is a developing country which a predominantly Muslim. Population has been facing increasing numbers of PLWH since the first case was identified in 1987. The country is known as having the fastest growing HIV epidemic in Asia (UNAIDS, UNICEF, WHO, & ADB, 2008). The estimated number of PLWH was reported in 2001 as 93,000 and has since increased to 270,000 at the end of 2007 (WHO, UNAIDS, & UNICEF, 2008). Unless prevention programs are effective, it is predicted that the prevalence of HIV would reach 500,000 by the end of 2010 (MoH, 2006) and 1 million by 2015 (AusAID, 2006). Bandung has the highest number of reported HIV/AIDS cases (MoH, 2009). The city with its 2.5 million inhabitants is located about 180 km southeast of Jakarta, the capital of Indonesia. HIV/AIDS reported in Bandung is predominantly found among injecting drug users (IDU) rather than in other risk groups (BACC, 2007).

United Nations has been rising its commitment by scaling up its HIV prevention, treatment, and care since 2005 with the aim of coming as close as possible to the goal of universal access to treatment by 2010 (UNAIDS, 2006). Care plays an important role in its efforts of tackling HIV and AIDS. Culture and care are usually embedded in daily practice of human being, both at individual and community level. It is imperative for healthcare providers to understand perceptions 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 (Smit, 2005).

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. Culture is acknowledged as a major determinant in caring for HIV persons (Lee, Keiwkarnka, & Khan, 2003; Wolffers, 1997). However, most studies on HIV and AIDS were conducted in Western and often lacked the Muslim context. This is why little is known about how persons living with HIV conceptualize care for themselves to be able to cope with it in a Muslim cultural context. The findings of the study may provide a practical knowledge to develop a culturally congruent type of care for people living with HIV.

Objectives

The purpose of the study is to describe the perceptions of care for self as told by persons living with HIV in the Muslim community of Bandung, Indonesia. The primary research question of the study is "what are the perceptions of caring for self when persons living with HIV in the context of the Muslim community of Bandung, Indonesia?"

Technical Terms

Perception of care refers to the meanings or values held by persons living with HIV infection in taking care by themselves. The term "caring" refers to assisting, supporting, enabling, and facilitating PLWH to maintain their health and well-being. This was reinforced and supported by the researcher's observations and explanations given by key participants and other stakeholders involved in caring for people living with HIV infection.

Research Methodology

This study is based on Leininger's theory of cultural care diversity and universality (Leininger, 2002). Cultural care theory concerns the close interrelationships of culture and care on well-being, health, illness, and death. Further, this concept elaborates *emic* and *etic* perspectives relating to life events including illness and health. The theory aims to discover and explain diverse and universal culturally healthcare practices and beliefs of individuals or groups in order to provide culturally congruent, safe, and meaningful care for clients of diverse or similar cultures. She recommended nurses to use a qualitative, ethnographic, or ethnonursing research method to examine and generate *emic* and *etic* cultural care nursing knowledge.

A focused ethnographic approach was utilized in this study to discover, describe, and systematically analyze the *emic* care conceptions within a specific cultural and environmental context. Leininger (1985) stated that the focused-ethnography or ethnonursing method was designed to tease out complex, elusive, and largely unknown forms of human care from the participants' perspectives. This approach enabled the researcher to develop insight into phenomenon of caring for persons living with HIV infection in the Muslim community of Bandung, Indonesia.

To gain trust of informants and allow contextual understanding of the phenomenon under investigation, the researcher who is an Indonesian, had immersed himself in the naturalistic setting. The Non Government Organizations' staffs working for HIV/AIDS served as gatekeepers, facilitating access to participants. His human relation skills and

fluency in speaking both Indonesian and Sundanese language (local language) has greatly facilitated winning the trust of the informants. 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 (Roper & Shapira, 2000). Thus, the researcher had to keep his preconceptions and values aside throughout the research process, while intimately interacting with informants and the data.

Twelve PLWH were selected to participate in this study. Data were collected through participant observation and by means of interviewing. In addition, eight family caregivers were also interviewed. 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. 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.

Data were analyzed on a daily basis. Initially data were written or transcribed in Indonesian language. Informants who spoke Sundanese were recorded and transcribed into Indonesian language. Furthermore, the researcher translated the data into English and asked an Indonesian English-teacher 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 (2002) 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. Trustworthiness of this study was ensured by the process of credibility, confirmability, and transferability as suggested by Lincoln and Guba (1985).

Ethical considerations

Ethical approval was granted by the Institutional Research Board, Faculty of Nursing, Prince of Songkla University, and the Health Research Ethical Committee, Faculty of Medicine, Padjadjaran University. The participants were well informed about the study objective and their right to withdraw from the study.

Study context

This study was carried out in a sub-urban area of Bandung City. Bandung's population is mostly Sundanese and Muslim (BACC, 2007). 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. The population density and high mobility of people, along with economic demands has posed a negative effect of increasing drug trafficking in the city (Hugo, 2001). Many young people engaged with illicit drugs, which led them to contract HIV. 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 loosing 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.

Findings

Four themes related to perceptions of caring for PLWH were described. Each theme, supported by patterns and descriptors, is presented in the following section.

Theme 1: Accepting destiny of being an HIV infected person while submitting self to *Allah* hoping for a better life

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 submitting self to Allah and hope everything will be fine in my future life" (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 way, just let everything go naturally. This is my way of life set by Allah. It has to be like this. I submit everything to the will of Allah. I hope I will get better in the future. This is a means of caring to me" (K6)*

Theme 2: Performing a maximum effort to maintain health

Nine key informants expressed their insight about caring for self as performing a maximum effort 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 every single individual, including me. I must continue striving for life by maintaining good health. To me, care means performing a maximum effort (ikhtiar) to keep healthy. I would do whatever ways to be healthy as long as it is plausible and relevant to my beliefs" (K8)*

Theme 3: Doing good deeds to compensate the previous mistakes related to HIV

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 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 return to the right way and living as commonly people here" (K1)*

> *"Even, the community health center occasionally asked me to lecture people about HIV/AIDS. I am happy to do that because it is a good chance to provide correct information to people, so they may not stigmatize people living with HIV. So, to me, caring means taking responsibility to do good things through sharing knowledge and experience about HIV and AIDS, and also as a proof of my worship to Allah" (K11)*

Theme 4: Fulfilling parenting responsibility

This notion of caring as fulfilling parenting responsibility was expressed by ten key informants. They were motivated to survive and to care for themselves in order to be healthy and be able to raise their kid(s). In their perspectives, caring can be meant as fulfilling the role of parent to grow up their children. In addition, seven key informants highly appreciated their parent, especially the mother, as the main source of support and encouragements. They expressed their gratefulness for genuinely family caring for them throughout the HIV illness trajectory. They acknowledged the responsibility of their parent in taking care of them. Even,

one key informant said that she had worries about rejection by her family previously when she disclosed her HIV status, yet it was unpredictable, but her family had warmly welcome her and comforted her from that moment on. Therefore she was happy to return home and stay with her parent. This is supported by the following statements:

> *"At that time, almost for 6 months, I kept my HIV status by myself. Only I and my husband knew it. I worried if I would tell it to my parent; they would be angry and rejected me to live with the family. Fortunately, my parent was fine and warmly accepted me and my husband. They were very caring since it was parent's responsibility to care for their children" (K8)*

> *"My mother is really helpful for me when I encounter the many life difficulties from facing HIV symptoms. She took me to hospital and guarded me during hospitalization. I really appreciated the responsibility of my mother in taking care of me. She is still very caring to me though I am HIV infected" (K5)*

Seven family caregiver informants supported caring for the sick family member who was infected by HIV as fulfilling parenting responsibility, regardless the types of illness or the stage of illness. They believed that the responsibility will be asked by *Allah* in the hereafter if they neglected here. This is supported by the following statements:

> *"Although he had engaged with bad behaviors of injecting drugs that caused him to get HIV infected, I still love him because he is my son. I wish to see him back to the right way and living normal life. It is my responsibility as his mother to care for him, if I don't care for him, Allah will ask me about this responsibility in the hereafter" (G1)*

> *"Only I and my wife who looked after him in this house. Yeah, although he suffered from such a terrible illness, we still loved him because he is our son. In our belief, having child is a mandate from Allah; we have to take care very well because Allah will ask our responsibility in the hereafter. So, this illness could be as a test for us whether or not we were able to carry this responsibility patiently. I noticed on the TV news that there was a group of people threw away a person with AIDS in another province. They shouldn't do like that, because they are humans. Our religion taught us to care for the sick regardless the type of illness. That is what caring means to me" (G8)*

Discussions

Findings of the study showed that their religious belief has sharpened the informants in construct the meaning of care from the *emic* perspectives. The three themes (no 1-3) were more likely reflecting a specific or diverse meanings of caring derived from Islamic cultural beliefs, while another theme (no 4) 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 perception and caring for people living with HIV infection (Aga, Kylma, & Nikkonen, 2009; MacNeil, 1996; Shambley-Ebron & Boyle, 2006; Songwathana & Manderson, 2001).

In this study, caring was perceived by the informants as accepting the destiny of being an HIV-infected person, while submitting self to *Allah* hoping for a better life. This reflects the cultural belief of the informant in understanding being HIV-infected. In the informants' view, destiny refers to a situation or condition that occurred already. They could not avoid or escape it, instead they had to accept it. This was congruent with a previous study that found religion as a source of strength and comfort in accepting the fate of being HIV infected or caregiver for an HIV-infected family member among Baganda women (MacNeil, 1996). In the Islamic perspective, destiny means a measure or the latent possibilities which Allah has determined when creating human beings and all things of nature (Hameed, 2002). It implies that *Allah* not only creates everything but also determines its nature and scope. By His infinite wisdom and mercy, He gave human beings a limited power and a great freedom, including the freedom of choice, yet he/she must be accountable for the individual deeds. Thus, destiny indicates that humans must seek harmony with *Allah's* rules about human nature and the universe and that they should continuously submit themselves to *Allah's* will. In this regards, destiny therefore should not make people utterly powerless or helpless, instead it can and often is a source of inspiration and encouragement. This belief has encouraged the informants to maintain hope for a better future life.

Performing a maximum effort to maintain health as expressed by the informants referred to utilizing any power or energy to search for the optimal treatment modality in recovering from an illness or maintaining health. The informants believed that *Allah* has set the best plan for every single individual, despite they were suffering from the present illness. It has reflected the notion of strong motivation to gain health as outlined by their religious beliefs. This is consistent with the Islamic teaching in which the informants and majority of the people in this study setting believe, suggesting that Muslims view illnesses, suffering, and dying as tests from Allah for patience and steadfastness of humans (Siddiqi, 2004). Muslims are encouraged to receive illness, suffering, and death with patience, meditation, and prayers. They should consider those as atonements for their sins, and death as a part of journey to meet their God. Thus, seeking appropriate treatment and care for sick person is strongly encouraged by Islam (Athar, 1999; Rassool, 2000).

Informants seemed to believe in the law of cause and effect in nature. They realized that their previous risky behavior has brought them into the present HIV status. This is also congruent with a previous study pointing out that suffering or pain resulted from AIDS illness was viewed as a punishment of previous sinful behavior, according to Buddhist beliefs (Songwathana & Manderson, 1998). This belief is also obvious in other religious beliefs such

as Judeo-Christian and Hinduism (Bergman & Collins, 2004; Das, 2010). The distinction between the "cause & effect" belief in Islam versus other religions is the foundation on which the belief is based. In Islam, the "cause & effect" belief is constructed as an essential part of natural laws set by Allah, the Oneness God who creates the universe including human being (Auda, 2002). It implies that "cause and effect" only fall within the will of God. In this study, the informants acknowledged their previous behavior as a mistake or wrong action according to existing norms. That way, they receive a negative effect, such an illness as warning or punishment for their sins. Therefore, they believe that only by asking forgiveness and doing good deeds might compensate or purify their previous sins.

Caring as social and cultural responsibility has been documented in previous studies (Aga, et al., 2009; MacNeil, 1996; Songwathana & Manderson, 1998; Yanwaree, 2002). In this study, caring was perceived by the informants as part of a parenting responsibility. It means that caring for a family member was inseparable from the obligation of being parent. This value has been taken for granted as a norm from previous generation. Violating this norm would result in disregard by the community and would socially be labeled as being an irresponsible parent. It reflects universality of caring whereby family members or a parent is serving an essential role as caregiver (Maneesriwongul, et al., 2004; Vithayachockitikhun, 2006). Many family caregivers believed that providing care for an HIV-infected family member was a responsibly or duty of the family (MacNeil, 1996; Songwathana & Manderson, 1998; Yanwaree, 2002). Despite family caregivers realized that caring for those person would impose a great burden, they showed a sincere willingness to care for HIV infected family member as it represents a sense of commitment to the family (MacNeil, 1996). In the Islamic perspective, Rasool (2000) asserted that caring is embedded in the theological framework of Islam. Caring is basically grounded on the belief of care as service to *Allah* or worship of *Allah*, which emphasizes the service should be freely from any other purposes except the blessing of *Allah*. Caring is the natural outcome of having a love for Allah and the Prophet Muhammad (PBUH). Caring, therefore, means the will to be responsible, sensitive, concerned with the motivation and commitment to act in the right order to achieve perfection of life. Thus, in practicing caring, Islam advocates the believers to follow the guideline set in the Qur'an and the Sunnah.

Conclusion and recommendations

This study presented "caring for self" has been constructed in various ways reflected universality and diversity of cultural beliefs and values. These were accepting destiny of

being HIV infected person while submitting self to *Allah* hoping for better life, performing a maximum effort to maintain health, doing good deeds to compensate the previous mistake related to HIV, and parenting responsibility. The findings of the study suggested the health care providers, particularly nurses, should recognize and acknowledge the cultural care in order to provide culturally congruent care for PLWH. Further studies on culture of care among others population in various cultural setting are needed to enrich evidences in transcultural care knowledge.

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