THE CONCEPTIONS OF HIV/AIDS AND LIVING WITH HIV/AIDS AMONG MUSLIMS INFECTED BY HIV IN BANDUNG INDONESIA

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ABSTRACT

Muslims form the largest section of the population in Indonesia, with their own worldview on health and illness, including HIV/AIDS. Little is known about how HIV-infected Muslims perceived HIV/AIDS in the cultural context of a Muslim community, in particular in Indonesia. This report is part of a large ethnography study aims to explore and describe the phenomenon of Muslim cultural care for people living with HIV/AIDS (PLWH) in the Bandung Community, Indonesia. Twelve informants (PLWH) participated in this study. Data were gathered over eight months by participant observation, interviews, and focus group discussions. The Leininger's ethnonursing phases of qualitative data analysis were used as the guideline in analyzing the data simultaneously with the data collection. Findings show the HIV illness as a deadly and dirty illness in the predominant conception about HIV/AIDS followed by HIV as a horrifying. Living with HIV/AIDS was perceived as being tested for faith and patience, time for doing self-evaluation and repentance, and shadowed by feelings of embarrassment. The findings suggest that nurses who work in the field of HIV/AIDS should be aware about the perceptions and meanings regarding health and illness, from the Muslim patients' perspective. Thus, it is essential to accommodate those cultural beliefs and values in designing culturally appropriate models of care for PLWH.

Key words: Conceptions, HIV/AIDS, Muslim, Indonesia

INTRODUCTION

The HIV/AIDS still a major problem and poses continual challenges to public health in many countries. The countries' leaders have signed a commitment to combat HIV/AIDS, malaria, and other diseases as a Goal of the Millennium Development Goals (MDGs) targeted by 2015. Indonesia is recognized as the largest Muslim country which is currently facing increasing numbers of people living with HIV/AIDS (PLWH). 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 310,000 at the end of 2009(UNAIDS, 2010). Unless prevention programs are effective, it is predicted that the prevalence of HIV would reach 1 million by 2015 (Australian Agency for International Development [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) (Bandung AIDS Control Commission, 2007).

United Nations has mandated its' country members to improve and scale up HIV prevention, treatment, and care with the aim of reaching the goal of universal access to treatment (UNAIDS, 2006). Care plays an important role in its efforts of tackling HIV/AIDS. Care is usually embedded in daily practice of human being, both at individual and community level. It is imperative for healthcare providers to understand conceptions of illness 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/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 HIV/AIDS and living with HIV/AIDS. The findings of the study may provide a practical knowledge to develop a culturally congruent type of care for PLWH.

METHOD

A focused ethnographic approach was utilized in this study to discover, describe, and systematically analyze the *emic* illness conceptions within a specific cultural and environmental context. Leininger (1985) stated that the focused-ethnography was designed to tease out complex, elusive, and largely unknown forms

of human phenomenon from the participants' perspectives. This approach enabled the researcher to develop insight into phenomenon of conceptions of HIV/AIDS and living with HIV/AIDS among Muslim infected by HIV in Bandung, Indonesia.

To gain trust of informants and allow contextual understanding of the phenomenon under investigation, the researcher immersed himself in the naturalistic setting. The Non Government Organizations' staffs working for HIV/AIDS served as gatekeepers, facilitating access to participants. Twelve PLWH were selected to participate in this study. Data were collected through participant observation, interviews, and group discussions. The researcher interviewed all informants in their home, which each interview being audiotaped and lasting 45 to 60 minutes. The researcher kept interviewing informants until sufficient data had been recorded, the saturation stage was reached.

Data were analyzed on a daily basis. Initially data were recorded and transcribed. 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).

FINDINGS

1. Conceptions about HIV/AIDS

The conceptions regarding the HIV/AIDS represented their understanding about the illness, were shared. Three themes related to perception of HIV/AIDS emerged which are described as follows:

1.1 HIV/AIDS is a deadly illness

Perception of HIV/AIDS as a deadly illness was initially expressed by all informants in this study. Informants perceived HIV was a deadly illness due to the fact that this illness causes death. However, they maintained that it could be managed by following medical prescriptions. The image of HIV/AIDS as a deadly illness was perpetuated by mass media that frequently displays the number of HIV-related deaths in the headlines. In addition, this perception became stronger after the informants witnessed their friends being diagnosed with AIDS and dying shortly afterward due to the delay in getting medical assistance. As one informant expressed:

"I think HIV is a really deadly illness and there are no available medicines to cure the illness right now. Previously I didn't pay much attention to this illness; yet, after I observed some of my friends dying due to AIDS, I became aware that I also was being exposed to this deadly illness." (K12)

1.2 HIV/AIDS as a dirty illness

Six informants, who were wives infected by their husbands, initially viewed HIV/AIDS as a dirty illness due to its association with a sexually transmitted infection, which in the local language is called "*raja singa*" (the lion king, referring to either syphilis or gonorrhea). Syphilis has been known for a long time by community's people as an illness that results from promiscuity. HIV was generally believed to be associated with promiscuity due to the fact that the earlier HIV cases were reported by mass media to be mainly found among sex workers. The informants were not really concerned about the biological cause of both HIV and syphilis because they thought it was invisible. They were mostly concerned with something that was more visible such as risky behaviors and their physical manifestations. The term 'dirty' might be associated with the manifestation of "disgusting" symptoms such as discharge form genital organs. The other six informants also associated the term "dirty" with promiscuity or extramarital sex *(zina)* as a prominent cause of HIV infection, which was also considered as "immoral". They believed that such behaviors were morally corrupt and considered as a sin according to their religious beliefs. One informant said:

"It is a dirty illness, so don't tell anybody else about this illness, otherwise I would get laughed at and mocked by them…I think it is 'dirty' because it is linked to promiscuity or 'zina' which is immoral and strongly prohibited by our religion." (K10)

1.3 HIV/AIDS as a horrifying illness

The serious impact of HIV on health and its label as "a dirty" illness has created another image of AIDS, that of a horrifying illness. A few terms such as "scary illness", "frightening illness", and "horrifying illness" were used to represent this perception. People were scared of this illness since they viewed it as a highly contagious and incurable illness, and as an illness that results from sinful behavior. When first diagnosed with HIV, all key informants experienced emotional shock and fear, and came to the realization that they had contracted an illness, which many people referred to as "a horrifying illness". However, they

learned to adapt to the new status of being HIV positive by developing positive coping strategies and utilizing available support resources. One informant (wife infected by her husband) eloquently expressed her insight when she encountered this issue in the following statement:

"At the beginning it was a really shocking and frightening experience for me. How come I got this illness? This is a horrifying illness because it cannot be cured and it is easily transmitted. People also may think, I am a prostitute and/or a sinful woman. I was depressed for several months. I could imagine how people would react to me if they knew I suffered from this horrible illness. Finally, I understood that this was a great test for me. I remembered of my late father's teaching that when God loves His servants, He sends down tests to prove whether or not they still have strong faith in Him." (K11)

2. Perception about living with HIV/AIDS

Being an HIV-infected person generated a deep insight among informants toward living with HIV infection. Perceptions about HIV and AIDS influenced the key informants' perception of living with the illness. In addition, media representations of HIV and AIDS, the real life experiences of key informants in dealing with HIV-related symptoms, and the perceived general public's response to this illness, helped reshape the construction of the meaning of HIV illness. The informants elaborated on their cultural beliefs and their role in understanding this illness in order to be able to live with this illness harmoniously. The explanations from informants and my observations confirm a particular perception which can be categorized into three themes which are described as follows:

2.1 Being tested of *iman* (faith) and *sabar* (patience) through the ups and downs of HIV-related suffering

Being HIV infected or an AIDS survivor with various kinds of pain-related and suffering-related symptoms the patients have gained significant understanding about living with such illness. The ups and downs of the prolonged experience of HIV symptoms, worsened by ARV medication side effects has led the informants to think transcendently by linking these experiences with the spiritual notions of *"iman"* and *"sabar"* in the Islamic belief. The term *iman* that could be literally translated into the proximate term of "faith" refers to the strong bonding between a creature *(makhluk)* and the creator (God), whereas *sabar* is literally equal with the term "patience", which refers to the ability to stay calm when facing with unpleasant or unexpected events. Both "faith" and "patience" were expressed by the informants to represent two essential beliefs in Muslim life that assisted them survive when facing difficulties. Being an HIV-infected person imposes a significant burden to the patient and his/her family that is difficult to manage. However, faith and patience helped informants to accept their condition as a test set by God for their *iman* and *sabar*.

The perception of living with HIV/AIDS as a test of faith and patience was stronger among the informants infected by the husband. They perceived their circumstance as a great test for them as innocent persons, because they had never engaged in any risky behavior before marriage. However, the participants realized that it could be a "risk" on a woman's part, if in ignorance or due to poor awareness about the potential of HIV transmission by the husband, she does not take into account this fact before getting married. Feeling regretful, angry, sad, depressed, and ashamed were the initial experiences of the informants who were infected by the husband. In addition, they did not only suffer from the illness, but also from the burden of being left without a husband, whom, culturally, serves as the backbone of the family. Four informants in this study were widowed as their husbands had passed away because of AIDS. All of them had young children still in need of much support to grow up into adulthood. The combination of being HIV infected and a widow, with the sole responsibility for child rearing, was perceived as imposing a great burden. Nonetheless, since this situation cannot be reversed and is here to stay, there is no benefit from feeling guilty and continuously blaming the husband. The informants tried to look at the situation from another side, which viewed it as a great test of their *iman* and *sabar* in carrying out their life. As one informant stated:

"I have suffered from many physical symptoms and psychological burdens resulting from this illness. Beside that, I have been widowed because my husband died because of AIDS, and I have to take care for my three children without any regular financial support. I think it is really a big test for my "iman" and "sabar" set by God." (K2)

The informants who were former IDUs mainly viewed living with HIV infection as either a warning or punishment from God for their past behavior. However, they agreed that this was also a test of their *iman* and *sabar*. They acknowledged that since their *iman* in the past was not strong enough they were tempted by drugs, which in turn led to their HIV infected. Being HIV positive was perceived as a test for their remaining *iman* and *sabar*. If they failed to go through the test patiently, they might succumb to thoughts of suicide or

self-destruction by rejecting or discontinuing taking the ARV medication. Taking good care of themselves, they assumed to be a sign of passing this test successfully. One informant stated:

"It is a great test from God, so I must receive it with patience. I actually do not want anyone to know about my story because it is such a sorrow to live with this illness…(tears are flowing down her eyes), my husband has gone already and left me with my little daughter in need of the necessities of life." (K3)

2.2 Time for doing *"mawas diri"* (self-evaluation) and *"insyaf"* (repentance)

Informants, particularly those with an IDU background understood and eventually accepted that the present HIV illness was a consequence of their previous behavior of injecting drugs. They thought that living with HIV infection meant they were given the opportunity to do *"mawas diri"* (self-evaluation) of their previous lifestyle and *"insyaf"* (repentance) from such negative behavior. They realized that they had committed sins by violating the Islamic religious norms. Therefore, God had sent this illness to them as a warning to repent and come back into the right way that is in accord with the existing social and religious norms. One informant asserted that if he had not contracted this illness, perhaps he would have still continued to immerse himself in the "world of illusions" of being a drug addicted until he would have died because of an overdose. "Repentance" among the informants' perspective refers to being very sorry for something bad one has done in the past and deliberately wishing to completely forsake such behavior in the present time and forever. One informant said:

"Being a drug addict was like living under shadows of illusion. Every day, in my mind, there were only thoughts of how to get drugs to satisfy my desires. I didn't care about others including my wife and son. I have lost many things such as money, property, time, and health as a consequence. So, when I got this illness, I thought this was a serious warning from Allah for me. I can imagine that if I did not get this illness, I would have continued to immerse myself in drugs. So, living with HIV now means that this is the time for me to do "mawas diri" and "insyaf, and not repeat the previous bad behaviors." (K1)

2.3 Shadowed by feeling of *"malu"* (embarrassment)

Informants thought that HIV is a dirt illness, and they perceived many people still believed HIV to be a consequence of immoral behavior, such as promiscuity or using drugs. They could not help feelings of embarrassment. They could commonly kept this feeling to themselves as long as other people did not know their HIV status; they could not warrant how they felt if people knew their HIV status. This made them see living with HIV/AIDS as shadowed by a feeling of *"malu"* (embarrassment). Therefore, to prevent extreme feelings of embarrassment, they kept their HIV status secret, especially for people in general, and attempted to behave normally. One informant stated:

"I think living with this illness means being shadowed by feelings of "malu". You know, I believe that many people still think that HIV is a dirt illness that results from promiscuity or immoral behavior. So it is better to keep secret my HIV status. If people know, I worry if they reject me or discriminate against me in this society." (K1)

DISCUSSION

The findings of this study present the influence of Muslim cultural values and beliefs on perceptions of HIV/AIDS and living with HIV/AIDS. These perceptions reflected the construction of the meaning of HIV/AIDS from the informant's point of view. HIV was perceived as a deadly illness due to serious impact leading to death. Although the advancement of antiretroviral therapy has proven to prolong the life of many of the PLWH, the image of HIV/AIDS as a deadly illness remains. This finding was congruent with a previous study which surveyed 3,517 respondents drawn from Muslim communities in four Asian countries (Bangladesh, Thailand, India, and Cambodia). The survey indicated that 86.2% of the respondents perceived HIV as a deadly illness (Charbley, 2007).

The physical symptoms of HIV/AIDS, which were initially noticed as sexual transmitted illness due to promiscuity or "immoral" behavior, has driven the perception of HIV as "a dirty illness". This perception still existed among informants who rarely are exposed to accurate knowledge about HIV/AIDS given by health care providers or NGOs. The term "immoral" to denote "promiscuity behavior" reflects Islamic cultural beliefs and was leading to seeing HIV as a dirty illness. This is relevant from previous studies, which highlighted that religious beliefs, such as Buddhism and Islam, has influenced the labeling of HIV as "dirty" which is linked to promiscuity or prostitution (Lake & Wood, 2005; Songwathana & Manderson, 1998).

The image of HIV as a "horrifying illness" was mainly associated with the serious impact of HIV/AIDS on health and its contagion. This perception was amplified by insistent media-campaigns, which frequently displayed HIV as a threatening illness. Lack of valid knowledge about HIV/AIDS has added to

the misperceptions among the general population. The misperceptions were in particular seen in the mode of HIV transmission, as was also found in previous studies (Ayranci, 2005; Lake & Wood, 2005). HIV as a fearful illness has been documented in previous studies. Khaliq (2004) found that most Somali Muslim Community members living in Minnesota perceived HIV/AIDS as fear, devastation, and danger. It was also reported by Charbley (2007) who found 74.4% of surveyed Asian Muslim communities (n = 3,517) perceived HIV as a fearful illness.

Conceptions about HIV/AIDS and the real experience of dealing with HIV infection have had a significant impact on "living with HIV infection". Being tested of *iman* (faith) and *sabar* (patience) through ups and downs of HIV-related sufferings reflected the inspiration of Islamic beliefs in constructing the meaning of living with the particular illness. Faith in Islam is defined as the state in which the heart accepts the truth of Islam and lives with it (Jamiat Ulamae Britain, 2010). The faith is convicted in the inner heart, professed by the lips and tongue, and executed by the limbs through actions in fulfillment the Muslim duties.

Al-Munajjid (2010) asserted that "patience" is the foundation of the Muslim's faith which has no other foundation. One who has no patience has no faith, or if he has any, it is only a little or very weak. In the Muslim view, faith and patience is most important in live because it engenders a personality which is strong, calm, not easily stirred to anger, able to think with clear mind, and able to undertake tasks properly an in an orderly fashion (Goddard, 2001). Thus, faith and patience become essential values of Muslim life when afflicted by life difficulties such as fear, hunger, loss of wealth, including illness and suffering. This is based on the revelation of the Qur'an: "And certainly, We shall test you with something of fear, hunger, loss of wealth, lives and fruits, but give glad tidings to as-Saabireen (the patient ones)" (Qur'an, 2:155). Therefore, living with HIV infection with ups and downs in suffering, resulting from HIV-related symptoms was constructed as being a test of faith and patience. If they can pass the test, they will get love from Allah as He stated in the Qur'an; "Allah surely loves those who are the *Sabireen* (patient ones)." (Qur'an, 3:146).

Living with HIV/AIDS has also created the meaning as "time for doing *'mawas diri'* (self-evaluation) and '*insyaf*' (repentance)". The fact that HIV is still an incurable disease has raised the awareness of PLWH on coming close to die. It has triggered them to do self-evaluation, reflection, and correction about previous behaviors which they might consider as deviant from the existing norms. Then, by doing repentance or quit from the risky behavior, they might get back to the right way in accord with the existing norms. In Islamic perspective, repentance (*tawbah* in Arabic) represents one who feels regret and is filled with remorse for his or her sins, when turning to Allah with the intention to obey Him (Benlafquih, 2009). Therefore, turning to Allah for forgiveness and mercy to release their sin could be identified as one pattern of living with HIV infection in this study. A Muslim's repentance must be genuine or sincere repentance, meaning a sincere effort to no longer oppose the God in one's feelings, thoughts, intentions, and acts, and to comply sincerely with His commands and prohibitions.

Shadowed by feeling of embarrassment was perceived as a meaning of living with HIV infection. This meaning indicates the perception about illness may have an effect on the personal feeling in the context of social and cultural interaction. Kobeisy (2004)asserted that the cultural pressure which focuses on image and appearance could be the source of shame for the patients who do not fit in this image. In addition, illnesses that result from the violation of religious values or cultural norms can also produce shame. In this context, informants felt shame or were embarrassed as they perceived HIV mainly as a dirty and immoral illness. This is relevant with Duffy (2005), who pointed out that being HIV-positive carries a strong sense of shame due to the reality of suspicion, fear, and being blamed by the general people.

CONCLUSSION AND RECOMENDATIONS

The study highlighted the influence of Islamic cultural values and beliefs in constructing the meanings of HIV/AIDS and living with HIV/AIDS. The health care providers, in particular nurses who considerably have more contact time with the HIV/AIDS patients than other health care providers, may take benefits of knowledge gained from the study. Nurses need to be aware about the influence of cultural beliefs and values on perceptions of illness which may drive patients' attitudes and behaviors toward health care seeking and practices. Further investigations are needed to understand which cultural beliefs and practices are promoting or impeding health care seeking behaviors as well as practices among PLWH.

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