Muslim Cultural Care for People Living with HIV Infection in the Bandung Community, Indonesia

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ABSTRACT

Muslims form the largest section of the population in Indonesia, with their own worldview on health, illness, and care, including caring for people living with HIV infection (PLWH). Little is known about caring for PLWH in the cultural context of a Muslim community, in particular in Indonesia. This focused ethnography aims to explore and describe the phenomenon of Muslim cultural care for PLWH in the Bandung Community, Indonesia. Twelve key informants (PLWH) and twenty-six general informants (family caregivers, health care providers, and community leaders) participated in this study. Data were gathered over eight months by participant observation, interviews, focus group discussions, and documentary analysis. 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 perception about HIV and AIDS. Living with HIV-infection was perceived as being tested for faith and patience, time for doing self-evaluation and repentance, and shadowed by feelings of embarrassment. The meanings of caring included (1) accepting the reality of having HIV infection while submitting themselves to God, (2) striving to maintain health by performing optimum efforts and supplication, (3) gaining the blessing of God by doing good deeds and worshipping, and (4) brotherhood and networking to share, support, and help each other. Informants developed various self-care strategies based on both cultural beliefs and modern health care practice. Caring and supports for PLWH provided by the family, the health care providers, and the community covered three main area: (1) physical care included nourishing the PLWH, reminding them to take medication, maintain cleanliness, and encouraging ways to manage symptoms, (2) emotional care included comforting, being with and helping PLWH, and (3) spiritual and social care included encouraging them to perform worship, accepting PLWH equally with others, and performing rituals for dying and death PLWH. Two categories of Muslim cultural beliefs and values were highlighted as associated with caring for PLWH, namely (1) facilitating caring included faith, brotherhood, patient and hardiness, equality, and cleanliness, and (2) impeding caring included covering disgrace and misconception about destiny.

The findings suggest that nurses who work in the field of HIV and AIDS care should be aware about the perceptions and meanings regarding illness, health, and caring 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.

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Kusman Ibrahim

CONTENTS

CONTENTS (Continued)

Page

CHAPTER

CONTENTS (Continued)

Page

CHAPTER

CONTENTS (Continued)

Page

CHAPTER

LIST OF TABLES

Page

TABLE

LIST OF FIGURES

Page

FIGURE

CHAPTER 1

INTRODUCTION

This chapter describes the background of the study, its purpose, the research questions, the conceptual framework, the definitions of terms, the significance, and scope of the study.

Background of the Study

Acquired Immune Deficiency Syndrome (AIDS) has reached pandemic proportions affecting millions of people men, women, and children around the world. There were an estimated 33.4 million people living with Human Immunodeficiency Virus (HIV) and AIDS in 2008 worldwide, and most of them live in developing countries (UNAIDS & WHO, 2009). Every day, over 6,800 people become infected and over 5,700 people die from AIDS due to inadequate access to prevention, care, and treatment services. HIV remains the most serious infectious disease with regard to public health (UNAIDS & WHO, 2007).

HIV/AIDS has been known for more than two decades and recent pharmacological interventions have resulted in a better bodily appearance of people living with HIV infection (PLWH). However, living with HIV/AIDS remains difficult and different from other illness. It is partly due to the stigma and other related problems attached to the illness. In developed countries, HIV related stigma perhaps is not a big problem nowadays because most of HIV/AIDS people are able to access anti-retroviral treatment (ART) and proper health-care services. In contrast, in most low and middle income countries access to the ART and health-care services are still limited and some people still hold the belief about the disease as a result of behavioral misconduct or other traditional beliefs (Kalichman & Simbayi, 2004). HIV related stigma, discrimination, and gender inequalities were also reported as dominant in six Asian countries include India, China, Thailand, Indonesia, Philippines, and Vietnam (Reidpath, Brijnath, & Chan, 2005). Stigma as a major barrier in mitigating the impact of HIV epidemic and accessing health care has been massively reported in the previous studies (Holzemer & Uys, 2004; MacQuarrie, Eckhaus, & Nyblade, 2009). Combating HIV related stigma and discrimination is still a major concern in caring for PLWH (Furber, Hodgson, Desclaux, & Mukasa, 2004).

Stigma and discrimination toward people living with a particular disease has been regarded as influenced by cultural beliefs, especially the beliefs related to health and illness (Link & Phelan, 2001). For example, the social stigma attaches to HIV/AIDS in a Muslim community is much more pronounced due to the religious doctrine condemning extramarital sex, homosexuality, and illicit drugs (Hasnain, 2005). Perception of AIDS as “a moral punishment” may lead people to divide PLWH into two groups: those who are “innocents”, such as a wife infected by husband and those who are “guilty” namely those who got infected through risky behavior (Helman, 2007). As a result, the general people in a Muslim community, may be less sympathetic to those who are guilty due to the violation of religious norms than those who are innocent. This, in turn, would inhibit the compassionate care for HIV-infected people particularly those who come from risk groups.

The United Nations (UN) have committed to a massive scaling-up of HIV prevention, treatment and care with the aim of coming as close as possible to the goal of universal access to treatment. The UN also addresses the HIV/AIDS as a social and cultural issue. Care or caring plays an important role in successfully tackling HIV/AIDS. Leininger (2002a) provided a great account to understand care in the context of culture and its implication for nursing care. Culture and care are usually embedded in the daily practice of humans being either at individual or at community level. Culturally sensitive care becomes an attractive issue to be understood by researchers, health-care providers, including nurses. Culture and care are complex phenomena which diverse meanings and expressions among various groups in different places. Such health care interventions should fit into the culture, beliefs, and ways of life among the population in order to achieve a meaningful result.

Caring for people living with HIV/AIDS is challenging due to the complexity, which need an interdisciplinary approach. In the context of health care, nurses are usually the largest group of health care providers who have regular and prolong contact with HIV/AIDS patients. Nurses are expected to provide high quality of care to the patients regardless their illness (Smit, 2005). The complexity of HIV/AIDS as a life threatening chronic disease has important implications, not only for individual affected person, but also for the family and the community. The family and community are probably the most important social systems that influence coping and adaptation of PLWH. As the problems faced within the family and community become clearer, there is likely to be a shift in focus in HIV care from the individual to the family or community based. This approach is seemingly much more acceptable in the Eastern as well as Muslim culture, in which collectivity of family and community is highly valued. Understanding the interrelationship among PLWH, their family, and the community in response to HIV/AIDS and how they care for HIV-infected persons within their cultural context is crucial to develop appropriate strategies in caring for people living with HIV infection.

Studies on caring for people living with HIV infection have been extensively published in the nursing literature. A number of the studies have been focused on the investigation of the impact of HIV/AIDS onto physical and psychosocial conditions of PLWH as well as on the experiences of nurses in caring for those patients. Culture is acknowledged as a major determinant in caring for HIV/AIDS people. However, most studies on HIV/AIDS were conducted in the Western and/or non-Muslim cultural context. There is little known about how PLWH live with the illness and how they experience caring in a Muslim cultural context, in particular in Indonesia.

Indonesia is one of the developing countries which face the problem of an increasing number of PLWH since the first case was identified in 1987. Recently, the country has been noted as having the fastest growing HIV epidemic in Asia (UNAIDS, 2008). According to the Ministry of Health of the Republic of Indonesia (MoH), by the end of December 2009 there were cumulatively 19,973 AIDS cases in Indonesia (MoH, 2009b). The estimated number of PLWH in Indonesia were 333,200 at the end of 2009, and if prevention programs do not work effectively, it is predicted there may be 541,700 at the end of 2014 (National AIDS Commission [NAC], 2009). The HIV prevalence in the general population of Indonesia was considered low, namely 0.22% in 2008 (NAC, 2009), if compared to its neighbor country Malaysia, namely 0.4% (MoH Malaysia, 2008). However, the prevalence continues to rise, in particular among risk populations. Injecting drug users was the highest prevalence, which constitutes 52.4%, followed by transgender *(waria)* 24.4%, commercial sex workers 15%, and homosexual 5.2% (MoH, 2009a).

There is a wide variation in HIV prevalence rates among provinces and cities in Indonesia. The Indonesia government has paid attention to the 100 cities already early, as they have in general a relatively large number of HIV infected people. Compare to other cities in Indonesia, Bandung is a city that reported as the highest number of PLWH which was 1,948 cases cumulatively up to March 2009 (MoH, 2009b). HIV/AIDS in Bandung is concentrated within high risk population groups, particularly intra-venous drugs users (IDUs) which constitutes 67.62%, and the majority of them are young adults, the most productive age group (Bandung AIDS Control Commission [BACC], 2007).

Living with HIV infection resulting from IDUs is likely to have a double stigma, namely the stigma of being HIV positive and of being an IDU, as that implies multiple health-care problems. My personal experience when working with PLWH before conducting this study reflected that many IDUs were reluctant to come to the clinic for HIV testing or health care service. Some of them got an HIV test in their shelter *(tempat pakaw)*[1] which was visited by Non Government Organization (NGO) staff. The NGO staff drew a blood sample and sent it to a health clinic for being tested. In some cases, PLWH died at home without receiving any proper care from health care providers. Wisaksana, van Crevel, Kesumah, Sudjana, and Sumantri (2009) conducted a study at a prominent HIV clinic in Bandung and found that almost 13% of the HIV patients who visited the clinic did not come to follow up during the last six months for unknown reasons. IDUs in particular were less likely to seek health care service, thus little is known about how these people were cared for and

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[1] *"tempat pakaw"* means a place that usually IDUs gathered to inject drugs (such as; heroin) together. Heroin in Indonesian language is called *"putaw"*, *pakaw* is 'short' from *pake putaw* (using heroin).

how they lived with HIV/AIDS. In addition, most HIV patients who came to the clinic have had already an advanced HIV-infection stage with symptoms such as severe wasting, candidiasis, pulmonary infection, and neurological problems.

Muslims are the vast majority of people in Indonesia who have specific beliefs and values that influence their way of life, including their view on health, illness, and care. In the Muslim point of view, health is one of the greatest blessings given by Allah (God) to human being (Al-Khayat, 1997). Care for health is an obligation for every Muslim as a means to preserve and thank for the blessing. Caring is an outcome of having obedience to Allah and the Prophet Muhammad PBUH[2] (Rassool, 2000). Muslims, therefore, are strongly encouraged to care for themselves as well as care for those who are sick. My personal experience when working in a public hospital reflects that Muslims were likely to show their empathy by visiting a relative or a sick community member. This reflects a cultural phenomenon of care which might influence care for the sick person. However, little is known how it is applied into caring for PLWH in the Muslim Community.

The demand of care for PLWH is expected to be high in the future, in particular in the cultural context of the Bandung Muslim population. To better understand the world’s view of a PLWH and surrounding people toward care for PLWH, a focus ethnographic study was selected as the most appropriate method to describe a holistic picture of Muslim cultural care for people living with HIV infection in the Bandung Community. It is hoped that this may be beneficial for further development of models of culturally sensitive care for PLWH in Indonesia.

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[2] PBUH means Peace Be Upon Him. This is required whenever the name of Prophet Muhammad (PBUH) is written

Purpose of the Study

The purpose of the study is to describe the Muslim cultural care for people living with HIV infection in the Bandung Community, Indonesia.

Research Questions

The primary research question was “what is Muslim cultural care for people living with HIV infection in Bandung Community, Indonesia?” The question then was subdivided into the following specific questions:

1. What do PLWH perceive HIV and AIDS and living with HIV infection?
2. What does caring means by PLWH and what are self-care activities performed by PLWH to maintain health and well-being?
3. What are health care and supports provided to PLWH by their family, by health care providers, and by the community?
4. What are cultural beliefs and values associated with the care for PLWH?

Conceptual Framework

The framework underpinning this study is based on the conceptualization of the culture care theory proposed by Leininger (2002a) and the assumptions that pervade Muslim people’s health care beliefs. Culture care theory argues the close interrelationships of culture and care on well-being, health, illness, and death (Leininger, 2002a). Further, this construct elaborates *emic* and *etic* perspectives related to life events including illness and health. The theory aims to discover and explain diverse and universal cultural health-care practices and beliefs of individuals or groups in order to provide culturally congruent, safe, and meaningful care for clients of diverse or similar cultures. The sunrise enabler provides a cognitive map to help researchers inductively discover the important elements of cultural and social structure that influence caring practices from the informants' perspective. Factors, such as technology, religion and philosophy, kinship and social, cultural beliefs, values, lifeways, political and legal aspects, economy, education, environmental context, language, and ethnohistory are considered as influencing factors toward expression, health-care practices and pattern. The three modes for congruent culture care are preservation or maintenance, accommodation or negotiation, and repatterning or restructuring. They are proposed to facilitate the achievement of health and well-being, or to face illness and ultimately death.

Muslim health care beliefs refer to Muslims' view toward health and illness and include actions to be taken to maintain health and well being. The beliefs are derived mostly from Islam religion. According to Al-Khayat (1997), Islam considers health to be one of the greatest blessings after faith, given to human beings by Allah (God). As a respect for the God's blessing, Muslim should be properly take care the health because it is believed that God will ask accountability of using the health during one's life encounter. The Prophet Muhammad (PBUH) also said: "No one will be allowed to move from his position on the Day of Judgment until he has been asked how he spent his life; how he used his knowledge; how he earned and spent his money; and in what pursuits he used his health" (Narrated by Al-Tirmizi and Abu Barza al-Aslami as cited in Al-Khayat, 1997). Therefore, taking good care, seeking appropriate treatment as well as doing preventive and promotive health measures are strongly recommended by Islamic teaching as long as no violation of Islamic laws occurs. In addition, the Qur'an[3] and the Sunnah[4] contain teachings that provide guidelines for every Muslim in protecting and caring for their health generally. Allah SWT (God Almighty) mentioned in the Qur'an: "We sent down in the Qur'an that which is healing and a mercy to those who believe: to the unjust it causes nothing but loss after loss" (Qur'an, 17:82). Islamic teaching instructs that illnesses, sicknesses, or diseases are considered as a test of life to be received with patience, meditation and prayers and be considered as atonements for the sins, and death as a part of journey to meet God in the hereafter. Muslims are supposed to look after, provide support, given attention, care, love, and affection for those who suffer a disease in order for them to lead their lives with dignity or to die peacefully (Athar, 1999; Rassool, 2000). However, the actual implementation of the Islamic teachings in daily life of Muslim may be influenced by several factors including knowledge of the Islamic teachings, faith, and their interaction with local cultural beliefs.

In this study, the cultural care beliefs and practices embedded in the Muslim community related to HIV/AIDS were explored and described. Care can be expressed in various ways, such as; assisting, supporting, enabling, encouraging, and providing resources for PLWH to assist them develop effective coping strategies that allow them to adapt to living well with HIV/AIDS (MacNeil, 2002). It is hypothesized that nurses, families, and the community willingness to support PLWH is influenced by their religious beliefs. Previous studies have found that kinship, the social structure of

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[3] Qur'an is The Holy Book of Islam; the highest and most authentic authority in Islam.

[4] Sunnah means practices undertaken or approved by the Prophet Muhammad (PBUH) and established as legally binding precedents.

society, religion, cultural beliefs and values, and lack of resources have impacted on perception of care providers and general community in caring for people with HIV infection (MacNeil, 1996; Nawafleh, Francis, & Chapman, 2005; Songwathana & Manderson, 1998). The unique manner in which PLWH, families, and communities deal with demands of the illness influence the degree and nature of individuals lifelong adjustment and well-being. As a nurse, the researcher believes that caring is more effective if all 'caring' modalities developed are sympathetic to cultural beliefs and lifestyles of the recipients of care. To achieve this aim, a comprehensive understanding of cultural beliefs related to HIV/AIDS and care for those infected and affected people from *emic* and *etic* perspective is necessary. Figure 1 is a conceptual framework reflecting the researcher's understanding of the interrelated concepts impacting on caring for PLWH in the cultural context of Muslim community.

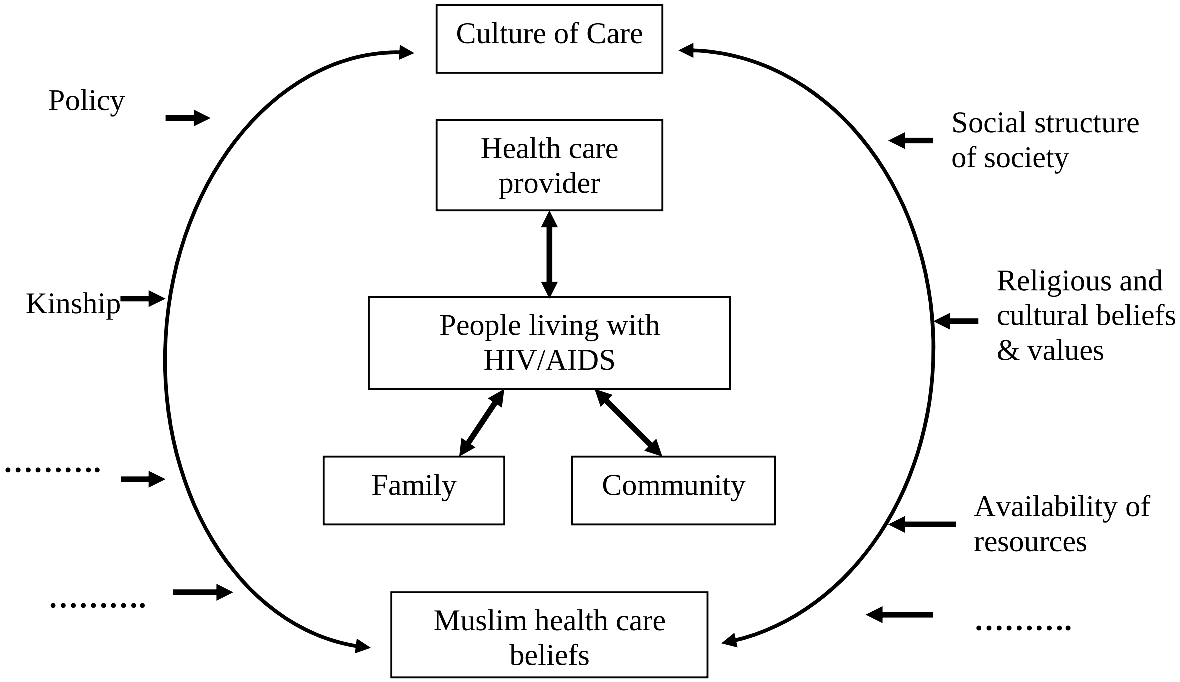

Figure 1 Conceptual framework of the study

Definition of Terms

Cultural care for people living with HIV infection refers to the perception, beliefs, values, and practices related to care for people living with HIV infection. This includes perceptions about HIV and AIDS and living with HIV infection, meanings of caring and self-care activities of PLWH to maintain health and well-being, care and support for PLWH provided by family caregivers, health care providers, and community members, and cultural values and beliefs associated with care for PLWH.

Muslim belief of care refers to the beliefs and values derived from Islam religion underlying behavior or actions in maintaining health and well-being, dealing with illness, and facing the death. This was concluded from the researcher's observations and also through explanations given by key participants and others involved in caring for people living with HIV infection.

Significance of the Study

The general findings of the study are aimed at being used to provide evidence as a foundation to develop a culturally sensitive model of community-based care for people living with HIV/AIDS. More specific benefits of this study to nursing are:

1. To gain a comprehensive understanding of experience in caring and living with HIV infection in a cultural context of Muslim community.

2. To provide baseline data for developing a model of community-based care for people living with HIV infection within their cultural context.

3. To contribute nursing knowledge in caring for people living with HIV infection in the context of Muslim community.

Scope of the Study

This study aims to explore and describe caring and living with HIV infection in the cultural context of Muslim community. Data was generated through extensive periods of engagement in a cultural context, in an urban area of Bandung District, West Java, a province in the centre of Indonesia, and was collected during eight months (June 2008 to February 2009). The key informants are people diagnosed of HIV positive and had known of HIV status, whereas the general informants are family caregivers, health care providers, and community leaders who had involved with the care for people with HIV infection.

CHAPTER 2

LITERATURE REVIEW

The literature review in this chapter is presented as follows: (1) HIV/AIDS situation in predominant Muslim countries in South and South-East Asia, (2) the Islamic belief and the Muslim culture of care, (3) caring for people living with HIV infection in Muslim communities, (4) health care system and HIV/AIDS care in Indonesia, (5) studies on caring for people living with HIV infection, (5) philosophical foundation of culture care and other related theories, and (6) ethnonursing methodology.

HIV/AIDS Situation in Predominant Muslim Countries in South and South-East Asia

In this context, predominant Muslim countries in South and South-East Asia includes Afghanistan, Pakistan, Bangladesh, Malaysia, Brunei Darussalam, and Indonesia, where the Muslim population in the countries exceeds 50%, according to their country profile (Organization of The Islamic Conference, 2007). All of these countries have either not reported at all or a low HIV prevalence until the early 1990s. Then, the incidence of HIV was growing up steadily in those countries. The WHO and UNAIDS estimated recently that the number of PLWH has still increased significantly from 2003 to 2005 in the named countries. For example, Indonesia, the most populous predominantly Muslims country, reported an increase in the number of HIV-infected persons from 110,000 in 2003 to 170,000 in 2005 (WHO, 2006). A similar development was also reported in Malaysia, Pakistan, and Bangladesh, whereas in Afghanistan and Brunei Darussalam, the number of PLWH was still below 100 by the end 2005 (WHO, 2006). However, analysts estimated the real number of HIV cases was far higher than the reported number (Ahmadzai, 2006). It is difficult to figure out the real number of HIV cases and underlying problems in the Asian predominantly Muslim countries due to limited number of rigorous studies conducted in the area. Most published HIV-related cases in these countries rely on government estimates.

Although some predominantly Muslim countries showed a low prevalence of the number of HIV cases, many of these countries suffer from risk behaviors of those groups that may fuel the HIV epidemic. Displaced populations and refugees due to post conflict situation, presentation of foreign militaries, limitation of infrastructure, low social and economic status of women, used of opium, and lack of employment has been highlighted as the main vulnerability factors of the HIV epidemic in Afghanistan (Bergenström, 2003; Reid & Costigan, 2002; Ryan, 2005). High rates of migrant workers, hidden practices of commercial sex workers, drug users, low level of knowledge about HIV/AIDS and its mode of transmission among a population, unsafe of needles usage in health care sectors, blood transfusion, and inadequate treatment of sexually transmitted diseases were identified as major contributing factors which lead to the spread of HIV in Pakistan (Khawaja, Gibney, Ahmed, & Vermund, 1997). Caldwell, Pieris, Khuda, Caldwell, and Caldwell (1999) found that one-quarter (N=983) of single males and a significant number of married males in Chittagong, Bangladesh, had had relationships with prostitutes. Men having sex with men (MSM) were prevalent and several among them were still engaged in sexual relation, with their current wives, female sex workers or girl-friends (Khan, Rodd, Saggers, & Bhuiya, 2005). In Malaysia and Indonesia HIV infections contracted through injecting drug usage were more dominant than heterosexual and homosexual activities (Huang & Hussein, 2004; Riono & Jazant, 2004). The practice of sharing needles among IDUs allowed HIV to spread rapidly (Pisani, Dadun, Sucahya, Kamil, & Jazant, 2003).

The evidence indicates that the incidence of HIV in Asian predominantly Muslim nations is increasing. Governments of these nations have formulated national strategies to address this problem. However, the implementation of the strategies was still problematic in some regions. Previous studies found a significant discrepancy between policies at governmental level and the implementation in the field (Foong, Ng, & Lee, 2005; Merati, Supriyadi, & Yuliana, 2005).

The Islamic Beliefs and Muslim Culture of Care

The Muslim population of the world consist 1.3 billion of various races, nationalities and cultures, which distribute in almost every country either as a minority or a majority population (Rassool, 2000). Throughout the world Muslims are connected by their common Islamic faith and heritage. Islam as a religion that is very close to the human nature that incorporates both ritual practices and a complete way of life. Muslims believe in One God; in the Angels created by Him; in God’s revealed Books, in the prophets through whom His revelations were brought to mankind; in the Day of Judgment and individual accountability for actions; in God's complete authority over human destiny and in life after death (Ibrahim, 1997). The Qur’an is a record of the exact words revealed by God through the Angel Gabriel to the Prophet

Muhammad (PBUH). It was memorized by the Prophet (PBUH), then dictated to his companions, and written down by the scribes, who cross-checked it during his lifetime. The Qur'an, the latest word revelation of God, is the prime source of every Muslim's faith and practice. It deals with all the subjects which human beings concern, including wisdom, doctrine, worship, and law. Its basic theme is the relationship between God and His creatures, and it also provides guidelines for a just society, proper human conduct and an equitable economic system. The five pillars of Islam are the framework of the Muslim life: faith *(sahadah)*, prayer (*shalat*), concern for the needy (*zakat*), fasting *(sawm)*, and the pilgrimage to Mecca *(Hajj)* for those who are able.

As a complete way of life, Islam has influenced the ways of life of Muslim which is reflected in their religious beliefs and practices. The cultural background and religious belief have an important influence on many aspects of people's life, including behavior, perception, emotion, language, family structure, diet, dress, body image, concepts of space and time, attitude toward health and illnesses, and care practices, all of which may have important implications for health care too (Helman, 2007). In the Muslim world, religion defines culture and the culture gives meaning to every aspect of individual's life (Hasnain, 2005). Muslims view health, illnesses, suffering, and dying as part of life and as a test from Allah. They are encouraged to receive illness, suffering, and death with patience, meditation, and prayers and consider as atonements for their sins, and death as a part of journey to meet their God (Athar, 1999; Rassool, 2000). Seeking appropriate treatment and care for any sick person is strongly encouraged by Islam. Moreover, health, illness, and caring become part of the continuum of human being in performing worship duties on the earth.

The Islamic view about caring is embedded in the theological framework of Islam (Rassool, 2000). The notion of caring in Islam is basically grounded on the belief of care as a service to Allah, the service of Allah's covenant purpose and is a free from any commercial basis. Caring is natural outcome of having love for Allah and the Prophet Muhammad (PBUH). Caring in Islam means the will to be responsible, sensitive, concerned with the motivation and commitment to act in the right order to achieve perfection of life. In doing so, Islam advocates the believers to follow the guidelines set in the Qur'an and the Sunnah. Prophet Muhammad (PBUH) has been sent as an example to mankind so his traditions in matters of health and personal hygiene are also a guide for his followers.

There are Islamic traditions that relate to health care practices which come along with the human life span. Islam views marriage as sacred and the family as the foundation of society, providing stability and security for both individuals and the family. Men are seen as the protectors of women, and play an important role in decision making to give consent for treatment. The patient's immediate family, even the community elders, should be considered when making decision regarding important treatment. Homosexuality is condemned, considered sinful and punishable by Allah. Muslim couples are encouraged to have children, sex outside marriage is discouraged, contraception and family planning are allowed, yet health care professionals should discuss appropriate methods with either the wife or husband. Abortion is not permitted, except if the pregnancy threatens the mother's life. Children are perceived as a gift from Allah, listening *adhaan* (the call for prayer) in the right ears and *iqaamah* (the announcement of the initiation for prayer) in the left ear of newborn baby, and receiving *tahnic* (placing a few sweet substance or honey on the newborn baby’s tongue) and *aqiqah* (shaving the baby’s head, naming the baby, sacrifice sheep), are encouraged by Islam (Amjad, 2000). Boys are circumcised, to enable them maintain ablution *(wudlu)* by preventing urine for collecting in the foreskin, which mostly takes place at the age of seven to twelve.

Muslims prefer to be cared for by someone of the same sex. The Islamic faith emphasizes cleanliness before any type of worship. Muslims prefer to wash their genitals with running water after using the toilet. Muslims eat with right hand and consider it rude to be handed anything with the left hand, eat only permissible food *(halal),* do not take non-permissible *(haram)* food, including pork, non-halal meat, alcoholic drinks, gelatin products, and illegal drugs. Organ donation and blood transfusion are acceptable. Human life is regarded as precious and taking a life through suicide or euthanasia is considered a major sin. A person certified as brain-stem dead should not be kept alive artificially, resuscitation is allowed, but in some cases the will of Allah should be allowed to prevail (Athar, 1999).

Muslims believe in life after death and the Day of Judgment. Sickness and suffering in this life are seen as a form of purification or recompense for wrong deeds. Terminally ill patients should be treated with sympathy and compassion and their spiritual need should be accommodated. Privacy is appreciated for a dying person, while declaring his/her faith *(talqin)*, or when reciting the Qur’an. When the person has died, the eyes and mouth should be closed, the body and limbs be straighten, and a complete ritual ablution should be performed either by family or by the attendants of the same sex as the dead person. The ceased should be covered with a plain sheet, and then be prayed over. The body should be buried as soon as possible (Athar, 1999; Sajid, 2003).

Caring for People Living with HIV Infection in Muslim Community

AIDS is a set of symptoms caused by the Human Immunodeficiency Virus (HIV). The HIV affects the body’s immune system, reducing its resistance to infection and illnesses (Noble, 2009). HIV is found in body fluids, especially semen, vaginal fluids and blood. Thus far there is no effective vaccine against the virus and there is no cure, once infected. Transmission of the HIV virus generally occurs through unprotected sexual intercourse, blood transfusions, use of non sterilized needles, organ transplants, and from mothers to their babies during pregnancy or at birth. The period of time from infection to the manifestation of recognizable AIDS symptoms can take anywhere from 6 to 10 years in adults. However, throughout that period knowingly or not, the infected person can spread the virus to others. The spread of HIV/AIDS is not just a health problem. It also has political, economic, social, ethical, religious and legal implications, which, sooner or later, will touch all aspects of the life of people in real and tangible ways.

Islam advocates a way of life which is based on good actions and activities and is free from evil, thus safeguarding the individual, the family, and the society at large from social and moral ills. Therefore, Islam prohibit extramarital sexual relationship and homosexuality, and bans alcohol, illicit drugs and others intoxicants substances. In fact, some Muslims are not fully following the Islamic teachings. Muslims have thus been observed after being engaged in those risky behaviors, which resulted in contracting HIV. Then, HIV was transmitted to their wives as well as from mother to child. In this regard, Muslims should realize that HIV really exists in the Muslim society as well, and should dedicate attention and effective efforts to prevent its spread and take responsibility to care for those infected and affected by HIV/AIDS.

Those who suffer from HIV infection should be aware that Islam highly values life and discourages hopeless or abuse of life. Muslims are supposed to look after life. HIV infected people are part of the Muslim community. Muslims should not avoid or neglect HIV-infected persons because of the disease. PLWH should be given attention, care, love, and affection, so they can lead their life with dignity. A Muslim has no right to judge or condemn HIV people; it is up to Allah Almighty whether to forgive or punish the people. Islam as a religion is full of compassion, love and mercy. As Allah Almighty said in the Qur'an: "… He joined your hearts in love, so that by His Grace, ye became brethren; and ye were on the brink of the Pit of Fire, and He saved you from it…" (Qur'an, 3:103). The Prophet Muhammad (PBUH) reminded Muslims that: "You will not enter into paradise until you believe, and you will not believe until you love one another" (Narrated by Muslim as cited in Ahmed & Miller, 2003).

In another Hadith[5], it is said, "Allah shows compassion only to those of his servants who are compassionate" (Narrated by Muslim as cited in Ahmed & Miller, 2003). Love and compassion are the qualities of a good Muslim, and people with AIDS cannot be denied these powerful emotions. Visiting and caring for the sick is another good deed that is highly recommended by the Prophet Muhammad (PBUH). "Whoever visits a sick person, is walking along the high road to heaven" (Narrated by Bukhari as cited in Ahmed & Miller, 2003). PLWH need compassion, love, support, and affection, therefore Muslims should be confident to embrace or touch them. The

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[5] Hadith is Prophet Muhammad PBUH's saying

Prophet (PBUH) also said, “If you enter the house of a sick person, then only speak good words, for truly the angels will confirm what you say, and they will open up the way to heaven for him” (Narrated by Nasa'i as cited in Ahmed & Miller, 2003).

Most Muslim communities practice the patriarchal culture system in society in which men as head of family have a great role in decisions making for family members. Religious leaders *(Imam)* are also important in decisions making for community matters. Prevention and caring programs addressed to Muslim communities should be appropriately discussed with heads of family, community as well as with religious leaders. Due to the high value of Muslim on family matters and collectivity, family or community-based care for sick person would be more preferred by Muslim.

Muslim in Asian countries may share similarities of religious beliefs with other Muslim elsewhere that derived from Islam. However, local culture and practices that are rooted in previous traditions still influence the way of life of Muslim people in the region. Concepts of spirituality, respect for ancestors, beliefs in spirits and mystics, and gender relations are examples of beliefs that derived from the pre-Islamic beliefs (Martin, 2004). Asian culture which stresses the maintenance of social and religious harmony with the universe, influences the attitude toward health and disease (Bhattacharya, 2004). For example, since HIV was viewed as an immoral disease, seeking health care for HIV infection or disclosing the sero-positive status could embarrass the family and community, coping strategy such as “keep silence” and “saving face” were utilized to maintain the dignity of the family and the community, resulting in that an HIV-infected person might be either isolated or rejected to live in the community (Bhattacharya, 2004). Busza (2001) documented several forms of stigmatization and discrimination toward PLWH that also existed in South-East Asian countries including those with predominantly Muslim inhabitants.

Health Care System and HIV/AIDS Care in Indonesia

Indonesia is a big archipelago country which covers about 2 million square kilometer of land area and consists of over 17,000 islands. About 1,000 islands are permanently settled by over 225 million inhabitants. The country is administratively divided into 33 provinces, 370 districts and 95 municipalities, 6,093 sub-districts, and 73,067 villages (MoH, 2008a). The geographical condition of the country, which is vulnerable to various natural disasters, and its culturally-diverse population of over 350 ethnic groups, imposes a significant challenge to upgrading the health care. The Indonesian government has taken several initiatives to protect the health of its population by formulating the National Health System *(Sistem Kesehatan Nasional)* as a guideline for health development. Indonesia’s health care system was founded based on the principles of humanity, human rights, justice and equity, community empowerment and autonomy, partnership, efficiency, and good governance (MoH, 2009). A long-term health development plan has been set up for a period of 20 years (2005-2025) aims to achieve “Indonesia Healthy by 2025”.

There are two modes of health care facilities in Indonesia, namely public and private funded systems (MoH, 2008b). Public health care facilities belong to government at large including the central government (Ministry of Health), regional government (provincial, districts/ municipalities), the Military Forces and the Police. Public health care facilities may include community health centers, clinical laboratories, specific hospitals, and general hospitals. Private health care facilities can belong to individuals, Profit Companies, or faith-based organizations. Private health care facilities can be in form of outpatient clinics, clinical laboratories, specific hospitals, and general hospitals. There are over 1,300 hospitals across the country, with various level specialty services from the district level hospitals up to top referral national level hospitals. About 50% of these are private hospitals.

Beside hospital-based care, there are community-based health care facilities provided by the Indonesia government. Community-based health care is provided by community health centers *(Puskesmas)* at sub-districts level and integrated service posts *(Posyandu),* village maternal huts *(Polindes)*, and village drug posts *(Pos Obat Desa).* Community health center are usually chaired by a physician to provide services, including maternal and child health care, general outpatient curative and preventative health care services, pre- and postnatal care, immunization, and communicable disease control programs. The village level services are run monthly by a visiting team from the regional health center assisted by local health volunteers *(Kader kesehatan)* and focus mainly more on maternal and child health care. There are over 8,200 community health centers nationwide, thus there are 3.65 centers per 100,000 people, so about 30,000 population per health center (MoH, 2008b).

The distribution of Indonesian health care workers is considered uneven. Most physicians prefer to work in an urban area rather than a rural or remote area. The Indonesian health care worker ratio is about 30 physicians (general practitioner), 158 nurses, and 75 midwifery per 100,000 population (MoH, 2008b). Due to the increasing population and growing demand for high-quality public health services, adequate financial resources are needed. Overall, the National budget for health care was only 2.64% of total national budget in 2009, which is far lower than the WHO’s recommendation of 15% (Lasti Kurnia, 2009). Although Indonesia has introduced some improvements into its health system, such as decentralization which empowers residencies and provinces to manage and finance health care, and the introduction of a health insurance system for the poor *(Askeskin)*, Indonesia is still encountering difficulties in implementing these health care reforms due to the lack of a systematic evaluation system. Moreover, not all residencies or provincial levels have equal capability to manage as well as subsidize the health care sector.

Beside the formal health care system, which is based on modern medicine, the traditional health care has also been developed and is used by the population since ancient times. The most popular traditional medicine, widely used in Indonesia, is *Jamu* (a mix of herbs). According to the Welfare Statistic year 2007, some 65% of Indonesians who were complaining about health problems still attempt to heal by themselves, and 28% of them selected traditional medicine to relief their disease symptoms (MoH, 2008b). In the recent years, numerous traditional healing methods have been growing up in line with demands from society. Some of traditional healing methods were also influenced by classic medicines from other countries such as India, China, and Arabia. However, most of the health care practitioners, especially physicians, do not acknowledge traditional medicine due to lack of evidence. This leads them to underestimated traditional healing methods as an integrated part of the health care system (Zein, 2005).

In respond to the HIV/AIDS epidemic, the Indonesian Government has devoted many efforts to find and implement an effective response in halting the HIV epidemic and mitigating its impacts. A National AIDS Commission (NAC) was established as a central body to coordinate several prevention, care, and control initiatives at national, provincial, district and municipality levels. The NAC developed the strategies to prevent and control HIV transmission. A National AIDS Strategic Plan for 2003-2007 and continued for 2007-2010 has been formulated (NAC, 2007). Indonesia has also signed the United Nations General Assembly Special Session Declaration of Commitment on HIV/AIDS (UNGASS) in June 2001, which is reflected in the global consensus framework, aimed to reach the Millennium Development Goals to reverse the epidemic by the year 2015 (NAC, 2006).

Several programs are adopted and implemented. The policy mandated the districts/cities government to implement minimal services in the following areas: (1) Behavioral Change Communication (BCC) and 100% Condom Use Programs; (2) prevention of HIV/AIDS through a response to sexually transmitted infections; (3) prevention of HIV/AIDS among IDUs; (4) Voluntary Counseling and Testin*g* services (VCT); (5) Care, Support and Treatment services (CST); (6) Prevention of Mother to Child Transmission services (PMTCT); (7) public communication services about HIV/AIDS; (8) HIV/AIDS services in the work place; (9) HIV/AIDS services in NGOs; (10) HIV/AIDS prevention in young people; and, (11) legal services, especially the publication of regional policies related to HIV/AIDS (NAC, 2006).

Currently, throughout the country there are about 547 health facilities providing VCT services, 180 sites offering ART services, 281 sites serving needle exchange program, and 46 locations presenting methadone substitution therapy service (NAC, 2009). Although the government has implemented many strategies and initiatives to control the spread of HIV in Indonesia, these have not been effective. The universal access policy that aims to facilitate the high risk groups in accessing prevention, care, support, and treatment programs did not effectively reach the ambitious target of 80% as set up in 2007. Data shows that by mid 2009 the programs only reached 51% of sex workers, 29% of IDUs, and 9% of MSM. It was also found that the ART service reached only 45% of those estimated to need the drugs (MoH, 2009a). Therefore, efforts needed to continue in order to reach the target of universal access by 2015.

Access to the ART is essential for people living with HIV infection to suppress the HIV virus and limit the progression of the disease. The Indonesian Government has been raising its commitment to provide free ART for those who are eligible since 2004. However, only 50% of them actually received the ART (NAC, 2009). Among those who are taking ART, 80% are still on the original first line regimens, and the rest either have changed one type of drug to another first line regimen, or changed to the second-line drugs. One among many concerns in providing antiretroviral service is sustainability of drug procurement. The recent data show that 5% of 180 ART sites experienced ARV stock out in 2009 due to limited supply, whereas every month about 450 new patients are eligible for ART treatment. Another concern about ART treatment is the level of adherence to ART medication. Although there is no known study to address this issue in Indonesia, available data reported that over 6% of those who are taking ART drop out from medication. That is probably due to intolerance to the side-effects of ART, as Ammassari et al. (2002) found that the adverse side effects of ART are one among several factors strongly associated with non-adherence to ART medication.

Nursing Service and Capacity Building in Caring for PLWH in Indonesia

Nursing services in Indonesia are governed by the Directorate of Nursing Service under the Directorate General of Medical Care, Ministry of Health. The Ministry of health provides technical assistances for developing the nursing service for both nurses who work under Ministry of Health and outside Ministry of Health. The Indonesian Nurses National Association (INNA) was established in 1974 as the overall nurse organization which aims to develop professionalism among Indonesian nurses. Unlike in other countries, there is no Nursing Council or Nursing Board, so there is no central regulatory body for nursing practice in Indonesia. Gradually, additional regulations on nursing practice were issued by the Ministry of Health. However, these are considered insufficient to provide full legal protection for nurses as well as for the society who receives the nursing service. Since Indonesia has no statutory council for nurses, it is difficult to assess the quality of health care professionals due to the lack of a national recognized standard (Hennessy, Hicks, Hilan, & Kawonal, 2006). This is a drawback of the practice of nursing care for PLWH both in hospital and in community settings.

As in many others countries, nurses constitute the majority of health care workers and serve as a front-liner caring in both hospital and community health care settings. This means that the quality of nursing care may reflect the quality of health care in general. Qualified nurses are necessary to deliver a proper nursing care to all clients, including PLWH. Therefore, appropriate knowledge and skills to care for PLWH need to be well prepared and updated by in-service trainings programs. With regard to caring for HIV/AIDS, the International Council of Nurses (ICN) has recommended nurses and midwives to be educated in the following areas: the modes of transmission of HIV, HBV, HCV and TB and how to prevent or reduce risk; “safer sex” practices; applying standard precautions; interpersonal skills to help deal with stigma and communicate effectively; safe injection practices; reducing risk of sharps or other injuries, e.g. passing sharp tools in protective containers rather than directly by hand; reducing stress and how to deal with sharps injury; using safer methods and procedures for sterilization, decontamination and handling of specimens; confidentiality and human rights including legislation, and regulation that protect the rights of patients and health workers (ICN, 2006).

In collaboration with the health officials of district and provincial level, the Ministry of Health has organized several training sessions, short courses, workshops, and seminars to improve nurses’ competence on HIV/AIDS care. Some of these include VCT, ART adherence counseling, IMAI (Integrated management of adolescent and adult illnesses), PMTCT, motivation interviewing, and universal precaution. However, the number of trained nurses may still be inadequate to cover the need of care of PLWH. This is compounded by the uneven distribution among the trained nurses in health care settings throughout the regions. In case of setting of this study which is largely community-based, a prior study showed there was a policy of the district health official to rotate nurses who work in community health centers (CHCs). As a consequence, some CHCs that have been appointed to run HIV services interrupted the services due to lack of trained staffs. Similarly, nurses who work in hospitals also lack proper preparation in caring for PLWH. Limited facilities and self-protective equipment in health care settings were also identified in previous study as barriers to supply a proper quality of care for PLWH (Nawafleh et al., 2005).

Studies on Caring for People Living with HIV Infection

A number of studies have been conducted concerning caring for PLWH, which show a great contribution on development of nursing knowledge related HIV/AIDS care. Although caring has been recognized as fundamental to and essential for nursing (Leininger, 2002a), research related care or caring has been also found in other disciplines. The earlier research on the area of care for PLWH were dominantly from developed countries and/or non-predominantly Muslim countries (Valimaki, Suominen, & Peate, 1998), therefore, in this review, the particular attention being paid to studies from predominantly Muslim countries and some others from developing countries. To reflect some issues on caring for PLWH, aspect of the caring issues were explored and presented in the following categories: (1) perception, knowledge, and attitude toward HIV/AIDS; (2) experience of people living with HIV/AIDS in receiving care; (3) nurses' experiences in caring for PLWH; (4) families' and communities' experience in caring for PLWH; (5) factors associated with caring for people living with HIV/AIDS, and (6) social stigma related HIV/AIDS.

1. Perception, knowledge, and attitudes toward HIV/AIDS

People's knowledge and attitudes toward HIV/AIDS and PLWH have been extensively researched. However, the field as a whole remains largely uncharted, particularly in the setting of Muslim countries as well as in developing countries. Early publications documented the association between knowledge, attitude, and willing to care for PLWH (Kussen & Niven, 1999). Therefore, understanding perception, knowledge, and attitude of particular people is crucial to raise the attention and care from those people. In Muslim community, some Muslims still hold the beliefs that HIV/AIDS is not an issue in their community. For example, in a population-based survey on knowledge, attitudes, and behavioral (KAB) towards HIV/AIDS conducted in Sudan, it was found that many Muslim people thought that HIV/AIDS could not a problem, it was problem of ‘others’, of prostitutes, of non Muslims, of foreigners. Muslim people were also reluctant to discuss sexual matters such as condom usage, homosexuality, sex workers, considered to be taboo. People were apprehensive about HIV/AIDS as a disease connected to immorality and tended to stigmatize those who suffered from it (Lake & Wood, 2005). Some people believe that contracting HIV/AIDS is a punishment from God for their sins. There is a gross misconception that the only way to become infected is through illicit drug use, male-to-male sex, pre-marital sex or polygamous relationships and it is certainly wrong to believe it is the wrath of Allah that has befallen them. This belief may lead to the attitude of stigmatization and discrimination of PLWH to be more pronounced among the Muslim community (Hasnain, 2005).

In Tunisia, Tebouski and Alaya (2004) reported that although most of the respondents correctly identify the main routes of HIV infection, some misconceptions about the role of condoms and false HIV transmission mode were existing, and their attitudes remain negative and unexpected. One-fourth of respondents (N=598) in their study blamed PLWH and thought that those people are responsible for their infection. In addition, the respondents thought that unsafe sexual behavior leading to HIV infection is considered a sin by Islam and by society, and heterosexual acts with a person other than the legal spouse are prohibited by Islam. The similar issues were identified by Nwokoji and Ajuwon (2004) from their study on Nigerian naval personnel reported that they still believe that AIDS affects only foreigners, and use of traditional medicine provides protection against HIV infection. Meanwhile, a quantitative study in Mali revealed that people who believed that AIDS was not real, instead it was seen as a punishment from God, a curse. It was taboo to talk about AIDS had higher fatalism mean score (Hess & McKinney, 2007).

A better knowledge and positive attitude was found in a study of Aryanci (2005) who reported that the Turkish population had a fairly good to excellent knowledge about HIV/AIDS. However, over 30% of respondents (N=1048) held misconceptions about HIV/AIDS such as AIDS as a heredity disease that can be contracted through sharing public toilets, swimming pools, personal items, food utensils, or even through exposure to cough or spits or urine of HIV infected persons. The overall attitude of the respondents toward HIV/AIDS and PLWH was positive and tolerant, while 23.2% of them believe that AIDS is punishment from God. Similarly, Montazeri (2005) surveyed 1172 Iranian people in Tehran and reported that the respondents demonstrated good knowledge about HIV/AIDS and positive attitude towards HIV/AIDS and PLWH. Few people thought that AIDS is not an infectious disease and mosquitoes are vectors of HIV. The majority of Iranian people do agree that lack of religiosity and moral commitments could cause HIV infection. Those evidences point out that some misconceptions and negative attitudes toward HIV and PLWH do still exist with various degrees among Muslim community. Unfortunately, studies reporting about perception, knowledge, and attitude of general people toward HIV and PLWH in predominantly Muslim countries in South and South-East Asia are scarce.

People living with HIV infection view a disease and themselves varied also in several ways. Mabunda (2004) reported in a qualitative study in South African that most informants (N=28) did not know much about HIV transmission before they joined a support group. They believed the myth that one could contract the virus by sharing even cleaned utensils that had been used by HIV infected persons and by sharing a bed with the persons. They also were reluctant to disclose their status for fear of losing their normal relationships with their families and community. Fear of abandonment, rejection and discrimination, violence, upsetting family members, accusations of infidelity, and eventually loss of economic support from a partner was identified among HIV infected women in developing countries that discouraged them to disclose their HIV status (Medley, Moreno, McGill, & Maman, 2004). Foong, Ng, and Lee (2005) conducted a qualitative study in Malaysia and found that PLWH in their study had a superficial knowledge and did not have a good understanding about HIV/AIDS in details, prior to their infection. Post infection knowledge about the disease commonly was obtained from health providers, family, friends and colleagues, and NGOs which have in-house educational sessions on HIV/AIDS. Some participants' attitudes seemed mostly fatalistic, showing hopelessness, and helplessness, while some others were desperately seeking information on potential cures and ways to cope with their problems.

Nurses, a large group of health care professional had also shown their own view toward HIV/AIDS. Chelenyane and Endacott (2006) conducted a study in Botswana and reported that nurses perceived themselves at risk of contracting HIV and fear of exposure to HIV/AIDS due to shortage of available resources. In Uganda, as in other developing countries, nurses also reported fear of contagion to HIV.

However, educational program facilitated nurses to have a proper level of knowledge which is associated with positive attitudes of nurses toward HIV/AIDS patients (Walusimbi & Okonsky, 2004). Similarly, trauma nurses in Kwazulu-Natal perceived themselves to be at risk of acquiring HIV/AIDS from their working environment such as needle stick injury, despite the available precautionary measures (Ncama & Uys, 2003). Nurses' fear of contagion were associated with carrying out certain clinical procedures on an HIV positive or high-risk patient, as the level of contact becomes more invasive and involves a greater possibility of contact with body substances, particularly blood, fear increases (McCann & Sharkey, 1998).

2. Experience of people living with HIV infection

Some studies revealed that experiences of people living with HIV infection are various. Fatigue as an indicator of the stage of HIV illness and progression had affected not only physical activity but also psychological and social life of HIV infected persons. Fatigue remained silent and invisible to HIV positive persons, their families, friends, employers, and generally lack acknowledgment and understanding from health care professionals (Jenkin, Koch, & Kralik, 2006; Rose, Pugh, Lears, & Gordon, 1998). Voss, et al. (2007) pointed out that perceived fatigue experienced by PLWHA was likely associated with acute symptoms of HIV disease. These HIV related symptoms were also reported to have negative association with perceived physical health (Phillips, Sowell, Rush, & Murdaugh, 2001). Stigma and discrimination continue to be a major issue despite HIV has been a public attention disease for over two decades. The stigma may occur within three contextual factors; environment, health care system, and agents including persons in the family, at the workplace and in the community (Holzemer et al., 2007). A study revealed that stigma, suffering, shame, and silence were experienced by PLWH living in rural Zimbabwe, where approximately one third of adults were HIV infected (Duffy, 2005). Dlamini et al. (2007) reported that extensive verbal and physical abuse and neglecting or disallowing of access to services and opportunities were likely experienced by PLWH who disclosed their status to family, friends, or community members. The situation caused HIV infected people living in suffering and uncertainty about their future life.

The complex physical and emotional problems of living with HIV demand HIV infected people to develop coping strategies to resolve those problems. Limited access to health care, especially in developing countries, had brought them to learn various self care strategies to manage symptoms, feelings, and emotions that came up from the progression of the disease as well as from response of surrounding people. (Klunklin & Greenwood, 2005) found that HIV infected women in rural Northern Thailand confronted four causally interrelated problems in their struggle to survive with HIV/AIDS: physical, economic, psycho-emotional, and socio-cultural, and they used two social processes to manage them: namely, “hiding out” and “hanging in” which refer to a range of very active strategies derived from both traditional Thai culture and Western medicine and aimed at allowing participants to make the best of their predicament. The strategies included learning to be accepted by others, acting normally, actively seeking support, securing financial assistance, and adopting a healthy lifestyle. Female adolescents with HIV/AIDS had been reported to use coping strategies such as listening to music, thinking about good things, making your own decisions, being close to someone you care about, sleeping, trying on your own to deal with problems, eating, watching television, day dreaming and praying (Lewis &

Brown, 2002). Some PLWH might use complementary therapies, prayer, nutrition supplements, and other as a self-care strategies method to promote their well being (Corless et al., 2002).

Those studies show that PLWH experienced various physical, emotional, and social-economical problems. Fatigue, suffering, uncertainty, stigma and discrimination, physical and verbal abuse, despair, hopelessness, and non adherent to medications were reported as the major problems encountered by PLWH. The coping strategies were also developed such as self-care symptom management strategies, actively seeking support, adopting a healthy lifestyle, lessening stress, and other strategies to manage their problems in order to survive.

3. Nurses' experience in caring for PLWH

The important role of nurses in caring for HIV/AIDS patients as well as raising people awareness toward HIV prevention has been cited in some literature. Understanding nurses' experience in dealing with PLWH may provide a better insight to be incorporated in strategies of prevention, treatment, care, and control of HIV. Smit (2005) conducted a qualitative study on nurses who care for HIV/AIDS patients in South Africa. She found that helplessness, emotional stress and fatigue, fear, anger and frustration, occupational-related concerns, empathy, and self-fulfillment were the most frequent themes reported by the participants. Nursing naturally placed nurses involved with terminally ill patients including the associate problems. Nurses who confronted AIDS patients in a dying process experienced emotionally powerlessness, relief, and fear (Bester, du Plessis, & Greeff, 2006). In addition, nurses were also involved in supporting death-hastening practices such as voluntary euthanasia or assisted suicide and believe that legislation for these practices needs to be established (Young & Ogden, 2000).

Nurses also expressed their experience of several barriers to the quality of care in caring for HIV/AIDS patients. In most developing countries in which health system has not been well organized; lack of essential supplies, staff shortages, overcrowded facilities, and lack of training were identified as a significant barrier to appropriate care for HIV/AIDS patients (Nawafleh et al., 2005; Talashek et al., 2007). The limitations had also hindered nurses to comply with universal precaution to prevent occupational risk HIV transmission (Chelenyane & Endacott, 2006). However, although nurses showed a great role in managing care resources, some nurses had minimal participation in health-care policy process and resource allocation (Phaladze, 2003). Individual barriers such as hopelessness, stigmatizing attitudes, knowledge gaps, and risky personal behaviors also inhibited the willingness of nurses to care for HIV/AIDS patients (Talashek et al., 2007). Nurses' willingness to care for HIV/AIDS patients were found significantly associated with nurses' feeling of preparedness to care, level of preparation of their workplace, their experience in AIDS care, and support from others (Preston, Forti, Kassab, & Koch, 2000).

Caring for HIV/AIDS patients is challenging and need a strong intention of care givers to cope with those various problems related HIV/AIDS. Sherman (Sherman, 2000) interviewed dedicated nurses regarding their experiences to cope with stress in caring for HIV/AIDS patients, coping strategies that commonly are used by nurses including taking the risk in their stride, reframing the risk, and protecting oneself, witnessing suffering, experiencing unresolved grief, accepting diversity, being emotionally connected, distress from the dismantling of the AIDS unit and work demands, balancing personal and professional life, releasing pain, respecting yet controlling feelings, managing demands, asking for help, and maintained spirituality. Several studies have been done by nurses to improve quality of care for HIV/AIDS patients. However, most of the studies have been conducted in hospital-based care, there were a few studies investigated caring practices for HIV/AIDS in community settings with regard cultural context of PLWH.

4. Family and community caring for PLWH

The increasing number of PLWH has brought a great impact on the structural relationships of families as well as communities. Families who had member(s) infected with HIV had also to deal with the complexity of HIV problems. Rehm and Franck (2000) found that the complexity of HIV problems and the need for stigma management prevent families from defining their lives as normal, but they do deliberately use normalization strategies to achieve the goals of health maintenance for members with HIV, facilitation of children's school participation, and enhancement of the emotional well-being of all family members. Pequegnat and Bray (1997) identified the problems experienced by families affected by AIDS: (a) trauma and fears about recurring acute illness episodes and impending losses; (b) grief for the loss of one's physical health; (c) isolation and rejection from other family members and friends, contributing to the deterioration of marital and nuclear family relationships; (d) uncontrolled emotions resulting from the illness (e.g., depression, hopelessness, feelings of loss, confusion, loneliness, fear, and suicidal ideation); (e) guilt about having infected loved ones and fear of further infection, either through physical contact or future pregnancies; (f) difficulty in maintaining any "normalcy" or routine in living and loss of predictability and control their life; (g) anxiety related to lack of financial support, sexual involvement, and medical outcome; (h) the overwhelming task of relating to multiple health and mental health providers, along with a lack of good medical care and counseling; (i) lack of available and affordable housing and related services due to stigma associated with HIV infection; (j) possible need to address problems of substance abuse and change in lifestyle; (k) lack of respite from providing care and expressions of concern because of the unavailability of alternative child care; (l) need to plan for bereavement and future of survivors; and (m) handling the stigma of a dreaded, immoral, and fatal disease.

Research on family as well as community caring for PLWH in developing countries is still limited. D'Cruz (2004) conducted a study to explore real-life experience of families in caring for PLWH in India. She revealed five themes from three categories of participants; 'losing autonomy following the diagnosis' and 'redefining family relationship in light of the need for personal care during illness episodes' emerged from care-recipients' participant; 'struggling to prolong the life of their HIV-positive loved one' was identified from HIV-negative caregivers participant; and from HIV-positive widows emerged themes as 'preserving the family over the course of the illness and after the death of the husband' and 'learning where and to whom to request confidential and appropriate social support'. In a review on family-care giving to persons living with HIV/AIDS in Thailand, Vithayachockitikhun (2006) pointed out that the common place for adult AIDS persons to spend the advanced stage of their illness is their parents' homes, and the most common caregiver is a parent, particularly a mother. An earlier study of caregivers using focus group in Thailand, reported that caregivers took responsibilities for caring for PLWH including providing physical care; assisting with activities of daily living (ADLs); cooking; giving medicine; physical exercise; wound care; providing basic care for general symptoms such as fever, headache, oral thrush, cough, diarrhea and skin infection; and giving emotional support (Maneesriwongul et al., 2004). These families experienced heavy burden related to financial limitations, inadequate resources and insufficient support. These findings underscore the effects of HIV/AIDS on families who care for their infected family members.

The tremendous impact of HIV/AIDS is not only to families but also to society as a whole. The society may lose their productive people who make the community strong or the loss of a young generation needed for the continuation of their society. Communities in which the PLWH live play an important role in providing care for HIV/AIDS people, especially in overcoming stigma and providing social support. Although research-based publications related to community-based care for PLWH are sparse, there are some community-based projects that have been carried out which reflected the care of the community for PLWHA. In Uganda, for example, Imams (Muslim religious leaders) from 850 mosques are including information about HIV/AIDS in religious lectures and Friday sermons. Qur’anic verses that deal with sexual ethics and integrity are being widely used in educational campaigns and counseling sessions. Nearly 7,000 community volunteers have visited more than 100,000 households since 1992 to spread the message about prevention. The success of this intervention is attributed to its use of the Islamic religious organizational structure as a vehicle for HIV/AIDS education. This project demonstrates that positive collaboration between health professionals and religious leaders can be achieved and then may enhance the success of community AIDS prevention efforts (Kagimu et al., 1998).

In Swaziland, Christian and traditional leaders are raising awareness about moral obligations to children, especially in the context of HIV/AIDS. In 2002, support services were provided to 38 per cent of all orphaned children in that country, more than double the number of children reached the previous year (UNICEF, 2003). The Sangha Metta Project was initiated by Buddhist monks in Thailand seeking to play a more active role in HIV/AIDS prevention and care. Taking the Buddha’s teachings as their starting point, they concluded that a core aspect of HIV/AIDS was ignorance about the condition both among those living with the disease and the general public. The project teaches monks, nuns and novices about HIV/AIDS and gives them the skills to work effectively in their communities. A crucial part of training is close contact between monks and people with HIV and AIDS, including accepting as alms food prepared by those with the infection. Sensitized in this way, the monks are soon able to work freely with affected individuals in remarkable ways (UNICEF, 2003).

Families and community have shown a significant involvement either in caring and supporting, or otherwise, neglecting and rejecting of PLWH. Uys (2003) found that more than a half of patients in her study died at home or in hospice and there was a significant relationship between a "good" death and dying at home among AIDS patients in South Africa. Similar with the Asian culture that value kinship and family relationship, it can be assumed that most of PLWH prefer to live and die in their own home. This highlighted the need of culturally sensitive home base or community base care for people living with HIV/AIDS.

5. Factors associated with caring for people living with HIV infection

Factors related to caring for people living with HIV/AIDS have been indicated in the previous studies. Religious as well as cultural beliefs and values are dominant in creating stigma for HIV/AIDS. A study in Southern Thailand conducted by Songwathana and Manderson (2001) found that villagers belief that AIDS as a result of doing bad deeds in previous life which were considered as sinful and immoral behaviors in Buddhist context. As a consequence, PLWH were likely to be stigmatized and discriminated in society. Social discrimination and stigmatization were also link with social hierarchy which was more often attached to poor people rather than to rich people. However, the beliefs of karma and loving kindness *(metta)* having emotive power associated with merit and encourage people to perform meritorious acts for those who suffer from HIV/AIDS. Religion was also viewed by Baganda women as a source of strength and comfort in accepting the fate of being HIV/AIDS people, loosing family members because of AIDS, and in the same time being caregiver for family who become HIV infected (MacNeil, 1996).

Kinship or family ties are acknowledged as important factor in caring for PLWH. It is particularly found in non-Western culture where most people are born and grow up in an extended family. Some of them placed family concerns before any individual concerns. Many family caregivers believed that providing care for HIV-infected family members was the responsibility or duty of the family (MacNeil, 1996; Songwathana & Manderson, 1998; Yanwaree, 2002). Therefore, a family may make a personal sacrifice to care for a HIV-infected family member. Despite family caregivers realized that caring for a HIV-infected family member would impose a great burden on them, they showed a sincere willingness to care for HIV-infected family members as it represents a sense of commitment to the family (MacNeil, 1996). The involvement of relatives, neighbors, and community leaders in providing support while visiting sick persons was also identified as a valid determinant to caring for PLWH (MacNeil, 1996; Songwathana & Manderson, 1998).

From the nurses' point of view related to factor associated with caring for PLWH, previous studies pointed out that lack of political implementations on the level of practice, limited resources, and less training of health-care staffs, lack of leadership and role models, cultural beliefs, and geographic location have influence the capacity of nurses to provide care for PLWH in Jordan (Nawafleh et al., 2005). Similarly, nurses in Uganda revealed that insufficient resources, fear of contagion, and lack of ongoing education resulting moral distress of nurses that led them to quit their job as nurses (Fournier, Kipp, Mill, & Walusimbi, 2007). In addition, proper knowledge and the right attitude of nurses had been important factor to determine the willingness of nurses to care for PLWH (Kussen & Niven, 1999).

6. Social stigma related to HIV and AIDS

Despite that the HIV epidemic has been occurred for over twenty-five years, HIV-related stigma and discrimination remains prevalent across the globe (MacQuarrie et al., 2009). Stigma and discrimination as major barriers in accessing HIV testing, care, and treatment, and as impediment adhered to treatment has been reported in many previous studies (Holzemer & Uys, 2004; Lawson et al., 2006; MacQuarrie et al., 2009; Songwathana & Manderson, 2001). The traditional definition of stigma was provided by sociologist Erving Goffman who referred to it as 'an attribute that is significantly discrediting' (Goffman as cited in Holzemer et al., 2007). Stigmatization can be conceptualized as a dynamic process that arises from the perception that there has been a violation of a set of shared attitudes, beliefs, and values. Thus, society labels an individual or a group as different or deviant which can lead to prejudicial thoughts, negative behaviors, and/or actions of discrimination (Brown, Macintyre, & Trujillo, 2003).

There are several factors associated with stigma. Lawson at al. (2006) found that religious beliefs and norms, homophobia, and silence about health and sexuality are affecting the response to HIV, and are the major factors that could increase the risk for stigma and isolation of PLWH. Stigma was correlated with basic knowledge related to HIV/AIDS, particularly traditional belief that the view HIV is caused by spirits (Kalichman & Simbayi, 2004). Holzemer et al. (2007) developed a model of the dynamics of HIV/AIDS stigma from his study. They found that the stigma process occurred within three contextual factors; the environment, the health care system, and the agent (person, family, workplace, community). It includes four elements: stigma triggers, stigmatizing behaviors, types of stigma and stigma outcomes. Stigma can be triggered by an HIV diagnosis or disclosure of the HIV status, a marker of difference that leads to suspicion of being infected. Stigma may lead to stigmatizing behaviors such as doing harm, isolation, excluding or identifying the person in a negative way. The three types of stigma are: received stigma which refers to all types of experienced stigmatizing behaviors, internal stigma that is thoughts and behaviors resulting from the persons' own negative perceptions about themselves, and associated stigma meaning that stigma which results from someone being close to or living with someone who is HIV-infected. The consequences of being stigmatized, or the outcome of stigma, can be poor general health, violence, a low quality of life, and a reduced access to care.

In the Muslim community, the literature suggests that social stigma attached to HIV/AIDS is likely to be stronger due to the religious doctrine of condemning illicit sex and drugs usage which is considered as primary mode of HIV transmission. Thus, HIV-infected persons were viewed as guilty or being sinners and it was believed that the sickness is a curse from Allah (Chamley, 2007; Hasnain, 2005; Lake & Wood, 2005; Sabur & Chamley, 2006). This belief can lead to blame, isolation, discrimination, and less sympathetic to those who are HIV-infected. The belief that disease is a curse from God may arise from the specific interpretation of a number of versus from the Qur'an. Proper interpretation of the Qur'an is indeed a difficult task due to the highly specific and nuance character of the Arabic language which may lead to different in translation and in understanding the verses of the Qur'an. In addition, Qur'anic verses can use different words or key-terms to describe sicknesses which may lead to different interpretation. Although it is understood in the context of the Qur'an in full with references to other verses as well as hadith, it can be argued that Islam does not promote a view of illnesses, such as HIV/AIDS, as a curse from God or punishment for wrong doing (Sabur & Chamley, 2006).

It is true that Islam strongly prohibits extramarital sexual relationship or adultery *(zina)*. Sheikh Ahmad Kutty (2006) pointed out that adultery is the most heinous of sins. Its enormity of this sin is not only due to its dire consequences affecting individuals, but also it entails infidelity and erodes the trust and tranquility that are the foundations of a fulfilling life of families and societies with peace, purity, and faith. If it is destroyed, it will expose the wrath of Allah which may result in eternal damnation. The presentation of AIDS can be partly assumed as a wrath of Allah because the human being did not follow God's orders. This belief can also influence Muslims' view toward PLWH, particularly in triggering negative attitudes or prejudices. However, Abdulwahab (2008) argued that Islam is a religion of compassion that does not tolerate human suffering in any ways. The stigmatization could be considered as a source of suffering for those who are HIV-infected, which is contradictory to the Islamic spirit of mutual right between members of society. Islam also does not recognize a double punishment for those who did wrongs, thus if HIV is viewed as a punishment from God then that punishment is enough and no person should stigmatize or discriminate PLWH. It is clear that stigma attached to HIV/AIDS mostly come from misinterpretation of Muslim people toward particular Islamic teachings rather than the religious belief itself.

Philosophical Foundations of the Culture Care and Other Related Theories

The phenomena of culture, health, illness, and care have drawn much attention of nursing researchers. As acknowledged by Helman (2007), a medical anthropologist who stated that nurses have been earlier than their medical colleagues be aware of the need to adapt clinical practice to the realities of an increasingly diverse society. The millstone of growing knowledge on culture and care can be trashed back to the first establishment of the ‘transcultural nursing society’ by Leininger in 1970s. Since the time, several theoretical models of cultural care have been developed and published in nursing literature. Amongst the well known culture-related theoretical models are: the theory of culture care diversity and universality developed by Leininger since 1950s (Leininger, 2002a), the cultural diversity in health and illness developed by Spector since 1977 (Spector, 2002), and the transcultural assessment model developed by Giger and Davidhizar since 1991 (Giger & Davidhizar, 2004).

Philosophically, the theories are developed based on the belief that in reality, all human beings, including nurses, are living in a global world and in diverse societies. It is believed that demography is destiny, demographic change is reality, and demographic sensitivity is imperative (Giger & Davidhizar, 2004). The change then impacts on the role of health care providers toward patients, families, and communities. Providing culturally appropriate and competent care in diverse societies becomes a complex and difficult task for many health care providers. A nurse who does not recognize the value and importance of culturally appropriate care cannot possibly be an effective care agent for his/her clients. Therefore, nurse researchers and nurse educators have devoted many efforts in answering questions such as ‘how could nurses learn about and respect cultural differences? How would nurses learn about cultures and their caring needs and practices? How do nurses discover, communicate, and understand the caring and health needs of their clients from a particular culture? Nursing needs to shift from the heavily emphasize on physical environmental health orientation into a much broader worldview and knowledge-base by incorporating trancultural nursing knowledge to guide nurses (Leininger, 2002a).

Theory of culture care diversity and universality is considered as the greatest theory in the field of transcultural nursing. It is widely used by nurse researchers to explicate knowledge-related culture and care among various populations with different cultural backgrounds. The main purpose of the theory is to discover and explain diverse and universal culturally-based care factors influencing the health, well-being, illness, or decease of individuals or of groups. Thus, the research findings using the theory may provide useful evidences to design culturally congruent, safe, and meaningful care for clients of diverse cultures (Leininger, 2002a).

In developing the theory, Leininger used a cultural construct from the anthropological perspective and care constructs from the nursing perspective. Leininger (2002a) defined culture as referring to the learned, shared, and transmitted values, beliefs, norms, and lifeways of a particular group that guides their thinking, decisions, and actions in a patterned way. Care is defined as abstract and concrete phenomena related assisting, supporting, or enabling experiences or behaviors toward of for others with evident or anticipated needs to ameliorate or improve a human condition or lifeway. Care consist of generic (folk or lay) care which refers to traditional or indigenous care, and professional care system which refers to care knowledge and skills which are taught and learned formally by health-care professionals. From the two main concepts, she synthesized concept of culture care, which refers to the subjectively and objectively learned and transmitted values, beliefs, and patterned lifeways that assist, support, facilitate, or enable another individual or group to maintain their well-being, health, to improve their human condition and lifeways, or to deal with illness, handicaps, and even death. Under the concept of culture care, she proposed concepts of culture care diversity and culture care universality which refer to a respective attitude toward differences and commonalities of care among many cultures.

Nursing is defined as a learned humanistic and scientific profession and discipline, which is focused on human-care phenomena and activities in order to assist, support, facilitate, or enable individuals or groups to maintain their well-being (or health) in culturally meaningful and beneficial ways, or to help people face handicaps or death. Three modes of nurses’ actions are identified to help people achieve health, namely cultural-care preservation or maintenance, cultural-care accommodation or negotiation, and cultural-care re-patterning or restructuring. Eventually, cultural congruent (nursing) care can be generated from applying this theory to which all care modalities fit with individual, group, or institutional cultural values, beliefs and lifeways in order to support meaningful, beneficial, and satisfying health care or well being. The Sunrise Model was created to depict the theory of culture care and to schematize several influencing factors to care expressions, patterns, and practices (Figure 2). The factors include technology, religion and philosophy, kinship and social, cultural beliefs, values, lifeways, political and legal, economy, education, environmental context, language, and ethnohistory.

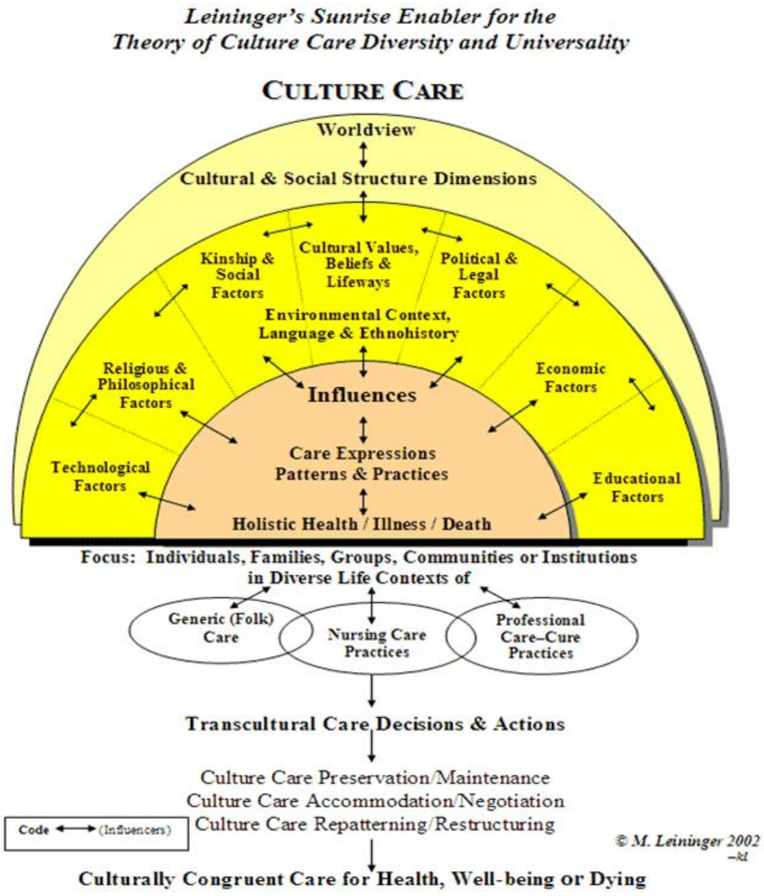


Figure 2 Leininger's sunrise model to depict the theory of culture care diversity and universality (Leininger, 2002a p.80)

Compared with Leininger’s culture care theory, Spector’s theoretical model on cultural diversity in health and illness is more abstract. However, Spector identifies several main concepts, sub-concepts, and other theoretical models to support her model. Three main concepts of Spector’s model are HEALTH tradition, heritage consistency, and cultural phenomena affecting HEALTH. The term “HEALTH” was used to distinguish with the meaning of “health” as stated by the WHO in 1948. HEALTH in the Spector’s model refers to a state of balance between the body, mind, and spirit as well as a sense of harmony with the environment (Spector, 2002). Under these three main concepts, she identified several related sub-concepts describes the definition of each sub-concept. Although clarification of the concepts and sub-concepts are given, Spector does not clearly address the assumptions, premises, and propositions that are relevant for her work. Giger and Davidhizar’s model of “transcultural nursing: assessment and intervention” also clearly identifies the ‘assumptions’ or metaparadigms as the foundation of their model. The main concepts and related sub-concept are explicitly described. According to Giger and Davidhizar (2004), this model is more addressed as a practical tool to assess cultural variables and their effects on health and illness-related behavior. Therefore, the scope is more limited than Leininger’s theory of cultural care.

In term of simplicity, Giger and Davidhizar’s model is sufficiently clear to be applied in practice. It is comparable to the theory of culture care. The Spector’s model is slightly more complicated since she borrows other theories without any specification and no clarification of which parts of the theories are more useful to support her model. Moreover, it seems to be overlapping among some sub-concepts. For example, Spector used the concepts of “biological variations” and “environmental condition" from Giger and Davidhizar's model to explain cultural phenomena affecting health. However, similar concepts such as cultural and ethnic variations are also used under the concept of heritage consistency, but need further clarification about their meaning and usage. Although the two models have various degree of simplicity, they are still less comprehensive than Leininger's theory of culture care.

Culture care theory demonstrates the criterion of generality because it is a qualitatively oriented, broad, and comprehensive theory that is worldwide in its scope. The theory addresses nursing care from a multicultural and worldview perspective, which is useful and applicable to both groups and individuals with the goal of rendering culturally-appropriate nursing care. Many aspects of culture, care, and health are identified because these factors have an impact on nursing. Findings from the theory are being used presently in client care in a variety of health and community settings worldwide. Spector's model has its scope mainly on understanding health and illness from traditional groups' point of view, Giger and Davidhizar's model has its scope on assessment of culture variables influencing care particularly in a practical setting. Therefore, in the context of cultural care, the theory of culture care has a much broader scope and can be applied in various cultures, settings, and levels of the client, including individual, family, group, and community.

Culture care theory is researchable, and the qualitative research has been the primary paradigm to discover largely unknown phenomena of care and health in diverse cultures. Leininger designed the ethnonursing research method to facilitate the discovery of data focused on the theory of culture care diversity and universality. The accuracy of grounded data derived from the methodology are from the people's viewpoint (emic) leading to high credibility, confirmability, and a wealth of empirical data. Although Spector's model and Giger and Davidhizar's model can be tested in research, and though Giger and Davidhizar also provide its instrument as a means for data collection, there is only limited empirical evidence using these models in the nursing literature.

Culture care theory has important outcomes for nursing knowledge development. Rendering culture-specific care is a necessary and essential new goal in nursing. It places the theory of culture care central to the domain of nursing knowledge acquisition and use. The theory is highly useful, applicable, and essential to the nursing practice, to education, as well as for research. The theory could be a means to establish a sound and defensible discipline and profession, guiding practices to meet a multicultural world. The models of Spector and Giger & Davidhizar have significant importance to generate knowledge related culture care as well. Spector's model emphasizes on how health and illness are perceived by particular traditional groups and how they maintain and overcome health problem in the traditional ways rather than investigating deeply on aspect of care. Thus, Giger and Davidhizar's model are more practical and can be used as guide to assess cultural dimensions of clients. However, those models are more appropriate to be applied in health care settings, which less acknowledges the natural setting of informants or participants.

Overall, among the three theoretical models related to cultural care as presented above, the theory of culture care diversity and universality is the only theory that is focusing on discovering holistic and comprehensive culture care. The theory provides a broad scope to inductively investigate a phenomenon relating culture and care which is possible to be applied in various populations of both Western and non-Western culture. However, since the phenomena of culture and care

are complex, the theory may still combine with, or lend from other related theories to explain the phenomena to become more holistically and comprehensive.

Ethnonursing Methodology

The ethnonursing research method was specifically designed to allow an in-depth study of the domain of inquiry. The ethnonursing research method is originally rooted on ethnography. The assumption underlying ethnographic inquiry is that any human group of people interacting together for a period of time may evolve a culture, and knowledge of all those cultures is valuable (Patton, 2002; Spradley, 1979). The philosophical underpinning of ethnography is rooted on the social constructivism paradigm (Patton, 2002). Constructivism begins with the premise that the human world is different from the natural, physical world and therefore must be studied differently (Lincoln & Guba, 1985). Human beings have evolved the capacity to interpret and construct a reality. Human perception is not something real in an absolute sense, but made up and shaped by cultural and linguistic construct (Patton, 2002). Constructivists study the multiple realities constructed by people and the implications of those constructions with others. Thus, the notion of “truth” becomes a matter of consensus among informed and sophisticated constructors, not of correspondence with an objective reality. Therefore, an objective fact has no meaning except some values attach to it. The constructivism believes that the nature of reality is relative *(ontological relativity)*. This means that all tenable statements about existence depend on a worldview, and no worldview is uniquely determined by empirical or sensed data about the world.

The term ethnonursing was coined and developed by Medeleine Leininger in the mid 1960s to facilitate the discovery of data focusing on the theory of Culture Care Diversity and Universality (Leininger, 2002a). Ethnonursing refers to a qualitative nursing research method focused on naturalistic, open discovery and largely inductive *(emic)* modes to document, describe, explain, and interpret informants' world view, meaning, symbols, and life experiences as they bear on actual or potential nursing care phenomena. Generally, ethnonursing shows similarities with the ethnography method; although ethnonursing focuses more on describing the culture of care as a nursing phenomenon and its implication for nursing. The ethnonursing method is a naturalistic (largely *emic* focused) and open inquiry mode to discover the informant's world of knowing and experiencing life. The research method is designed to focus on *emic* and *etic* knowledge and practices related to care, health, well-being, illness, lifecycle experiences, dying, disabilities, prevention modes, and other nursing phenomena.

To facilitate in-depth discoveries of the informants' world of knowing, Leininger developed five enablers to tease out data bearing on culture care, health, and related nursing phenomena. The five enablers are (1) observation-participation-reflection enabler, (2) stranger to trusted friend enabler, (3) sunrise model enabler, (4) specific domain of inquiry enabler, and (5) acculturation enabler. The first enabler is a helpful and essential guide to enable the researcher to enter and remain with informants in the familiar or natural context. The researcher moves from an observer and listener role to gradually a participant and reflector role with the informants in the phenomena under study. The second enabler helps the researcher to be a stranger in an unfamiliar environment, who is looking for new ideas of informants and responses and not assuming “one knows all about them and their culture”. With this enabler, the researcher can learn much about oneself and the people under study. Afterward, the researcher may move from a stranger to be a trusted friend. It means being trusted for honest, credible, and in-depth data from informants. The third enabler is a comprehensive guide for researcher to tease out data related to multiple factors influencing care and health outcome and to remain cognizant of holistic lifeways to be examined by the culture care theory. The forth enabler is specific to the researcher’s interests and focuses on the domain of study. This is a succinct tailor-made statement focusing directly and specifically on culture care and health phenomenon. Finally, the fifth enabler is used to assess the extent of acculturation of the informant whether more traditionally oriented in their values, beliefs, and general lifeways.

The major reason for choosing ethnonursing, or in another term named “focused ethnography” (Leininger, 1985), is the appropriateness of the research design with the study purpose that aimed to describe the phenomenon of caring and living with HIV/AIDS in the cultural context of the Muslim community in Bandung Indonesia. As it is based on qualitative inquiries, ethnonursing is a suitable research approach when there is limited existing knowledge about a particular phenomenon (Leininger, 2002a). So far, no study has been found which examines the phenomenon of Muslim cultural care for people living with HIV infection in the cultural context of Bandung community, Indonesia. By employing the ethnonursing method the researcher wishes to grasp the totality of a human lifestyle or to capture a broad worldview about individual, families, and cultures from informants’ perspectives and their mode of knowing and understanding life.

Summary

HIV has spread worldwide and now includes the predominantly Muslim countries in the South and South-East Asia. Although the prevalence of HIV is considered to be low in these countries, among the high risk groups such as sex workers, IDUs, and homosexuals the incidence is alarming. Most of the countries show similarity in the dominant modes of transmission through extramarital sexual relationships and IDU. The governments of the countries have devoted many attempts in response to the HIV epidemic by formulating various strategies in prevention, care, support, and treatment for HIV/AIDS, though the implementation of those policies seems still problematic.

HIV/AIDS is a complex global health problem. Culture and beliefs are acknowledged as important factors that influence the policy and the treatment of HIV/AIDS. In the Muslim worldview, Islamic religion has a strong influence on Muslim people’s beliefs about health, illness, and well-being. Nurses, as the largest group of health care providers, need to take into account culturally diverse worldviews of people in order to provide quality nursing care. A number of studies have been carried out in the field of caring for PLWH, however, there is little known about cultural care for PLWH in a typical Asian Muslim context.

The theory of cultural care diversity and universality serves as a primary theory that is widely used by nurse researchers as a guide to investigate cultural care phenomena among various populations. The “Sunrise model” as described by Leininger provides guidance to health the researchers in allying the theory of culture care into research to generate knowledge about culture care.

CHAPTER 3

METHODOLOGY

This chapter describes the methodology used for this study. It presents the research design and methods which are organized into the following sections: the research design, study setting and context, informants, data collection process and methods, instruments, data analysis, trustworthiness, and ethical consideration.

Research Design

This study utilizes focused ethnographic approach, or ethnonursing, to discover, describe, and systematically analyze the Muslim cultural care for people living with HIV/AIDS in the Bandung community, Indonesia. Leininger (1985; 2002a) stated that ethnonursing method was designed to tease out complex, elusive, and largely unknown forms of human care from participants' perspectives. This approach enabled the researcher to develop insight into phenomenon of care for people living with HIV infection in Muslim cultural context.

Study Setting and Context

This study took place in an urban area of Bandung District, West Java Province, Indonesia. West Java Province is a part of western Java Island (Figure 3). The province stretches from Sunda Strait in the west to the border of Central Java in the east. The West Java province is formed based on the Constitution number 11/1950 on the establishment of West Java Province. Administratively, West Java consists of 17 districts, 9 municipalities, 604 sub-districts, 4,029 villages and 1,798 *kelurahan* (equivalence to village, yet located in urban area) and had a total population of 41,483,729 inhabitants in 2007 (Provincial Heath Office of the West Java Province, 2008). The area of West Java covers 35,746.26 kilometer square with the second highest population density, after Jakarta, namely 1,140 inhabitants per square kilometer.

Figure 3 Map of Indonesia (Source: http://internationalsilatfederation.com/regions.php)

West Java Province is also called “the Land of Sunda” ("West Java," 2008). The region is primarily mountainous, with rich green valleys hugging lofty volcanic peaks, many of which surround the capital of West Java province. This province has its own unique culture and language, both called Sundanese, a name which is also used for its people. The Sundanese are the second-largest ethnic group in Indonesia, after Javanese. There is a complex history behind their rich cultural traditions. This history can be traced back to the fifth century AD and the Tarumanagara dynasty, which established trade links extending as far as China and India. A succession of Sundanese kingdoms was followed by 350 years of Dutch colonization. During this time Sundanese lands became an important source of spices, coffee, quinine, rubber, and tea for export.

Like other Indonesians, most Sundanese are bilingual. They speak both their native tongue, Sundanese, and the Indonesian national language *(Bahasa Indonesia)*. Generally, Sundanese is the language of choice among family members and friends, while in the public sphere, Indonesian is used. Sundanese language possesses elaborate speech levels with regard to age (younger, equal, older), and social status in society. A tradition of respect (*hormat*) is taught to the children as a code of conduct toward elder and those who have proper position in society ("Sundanese," 2007).

In some rural areas, when a Sundanese child is born, a *paraji* (traditional birth attendant) is usually present to provide advice. The paraji also prays to help the mother and the newborn get through the delivery safely. Once the baby is born, its umbilical cord is cut with a special instrument called a *hanis.* The placenta is buried beneath a window at the rear of the house. A ritual party is held, attended by family and neighbors. At the age of seven or eight year, boys undergo a circumcision ritual to usher them into adulthood. Before the circumcision takes place, the boy is bathed and dressed in a *sarong* (a skirt-like garment). The entire ceremony takes place at the boy's home, and is frequently accompanied by a party (Ekadjati, 1984).

Friends and relatives immediately gather at the house of serious sick or dead a community member. They bring gifts of money and rice for the family. Flowers are soaked in water, which is used for washing the body of the deceased. A religious leader *(kiai)* lead a group to recite the Qur’an and pray over the body before it is carried in a procession to the cemetery. The death is later marked by ritual gatherings on the third, seventh, fortieth, one-hundredth, and one-thousandth days after the person has passed away.

Sundanese society draws a clear line between male and female gender roles. Men are regarded as the head of the family and are responsible for the family's income. Meanwhile, women are responsible for running the household and taking care of the children. If additional help or income is needed, however, wives also work outside the house. Among Sundanese villagers it is common for husbands and wives to work together either in agriculture or in small-scale business activities. Nowadays, some women in the cities are economically independent from their husbands by taking on careers or part-time jobs to earn additional income (Suhamihardja, 1984)

Kinship among the Sundanese is bilateral, meaning that descent lines are traced through both the mother and the father. In principle, all the descendants of a seventh-generation ancestor are members of one extended family. The smallest kin group is the nuclear family of parents and their children. Members of a nuclear family usually live in their own house. However, it is common for relatives of either the husband or the wife to stay with them for a time (Suhamihardja, 1984).

Living conditions in West Java are extremely diverse. Some people live in luxurious tropical mansions, while others live in squatter settlements with no running water or electricity. Most people live somewhere between these two extremes. Unemployment is not as great a problem as is under-employment in West Java. Most people have some way of generating income, but they still have a hard time making ends meet. Even the new generation of college-educated youth is having a hard time finding work. When a job does open up, it is often for very low pay at one of the new factories that produce sneakers, televisions, clothing, or furniture. Such positions are usually filled by young women and uneducated men. Many jobs are filled by migrants from other parts of Indonesia who are more willing to work more hours without vacations than are the family-oriented Sundanese (Garna, 1984).

Although there are Catholics and Protestants, the vast majority of Sundanese is Muslim and has strong ties to Islam. Many Muslims pray five times a day, travel to Mecca at some point in their life, and fast during the holy month of Ramadan. In towns and cities, there is a mosque in every neighborhood. Each day the calls to prayer are broadcast over loudspeakers for everyone to hear. Islam is a particularly visible and audible presence in the life of the Sundanese. On Friday at noon, sarong-clad men and boys fill the streets on their way to the mosques to join the midday prayer known as the Jum'atan, which provides the visible definition of the religious community in the Sundanese community. However, in some area, there are still many non-Islamic elements in Sundanese ceremonies and rituals, particularly classical aspects related to the growing of rice. As Islam came to the Sundanese, the five major pillars of the religion were emphasized but in many other areas of religious thought a syncretism developed with the original Sundanese worldview. Scholars believe Islam accepted that the customs which benefit society should be retained. Thus Islam was mixed with many Hindu and ancient customs of the people that existed preceding the spread of Islam (Dixon, 1999).

The Sundanese place great value on showing people respect by following an unwritten code of behavior. Formal greetings are made by bowing the head and upper body. The hands are held together in front of the chest with fingers outstretched, and the fingertips touch the tips of the other person's fingers. In business settings, handshaking is acceptable. The Sundanese people possess uncommon warmth along with courtesy, friendliness and politeness. They have a strong sense of helping each other when in need. Islam rules now many customs and traditions of Sundanese in multiple facets of their life, in particular health beliefs and health care practices ("Sundanese," 2007).

Bandung is the capital city of West Java province. The city gained fame in 1955 as the venue for the first Afro-Asian Conference, which brought together the leaders of 29 Asian, and African nations with the aim to promote economic and cultural relations and take a common stand against colonialism. Bandung is located about 180 km southeast of Jakarta, the capital of Indonesia. It is situated on a plateau some 768 meters above sea level, surrounded by mountains with a cooler climate throughout the year. Bandung is the fourth most populous city in Indonesia with over 2.5 millions inhabitants who populate almost 168 km^2. Bandung is known as a rather interesting city with many old art-deco buildings, beautiful parks and fine landscapes. In the past, it was well known as the “Parijs van Java”, due to the beauty of the city. After Indonesian independence, the city experienced a rapid development and urbanization that influenced all facets of societal life. To date, Bandung is a popular weekend-break destination for people living in Jakarta for several reasons, like the cooler climate of highland plantation area, the varieties of food, the cheaper fashion shops located in factory outlets, golf courses, and the friendliness of local people. Bandung’s economy is mainly built upon farming, tourism, manufacturing especially textile, education at various levels, technology, retailing, pharmaceuticals and food, among others. Most of Bandung’s population is Sundanese, and the rest are Javanese, Chinese, Malays, Indian, Korean, Batak, and various ethnic groups originating from other part of Indonesia ("Bandung," 2007; Bandung City," 2006).

Informants

Informants in this study consist of two groups: key informants and general informants. In Bandung community, informants were selected initially by using purposive sampling on the basis of several criteria that fit with the aim of the study. Key informants are people who have been diagnosed as HIV positive with inclusion criteria; (1) knowing their HIV positive status for at least six months, (2) Being an adult Muslim, (3) having experience in receiving care from nurses, (4) living with his/her family in the same household, and (5) able to speak and understand either Sundanese or Indonesia language.

General informants consist of major care providers among family groups, nurses who have experience in caring for PLWH, community leaders and community key persons such as religious leaders and community health volunteer *(kader kesehatan)*. The number of key and general informants in this study was determined by informational considerations (Lincoln & Guba, 1985). The information was considered as saturated when no more new information was forthcoming. However, literature suggested that an ethnographic approach commonly requires 30-50 informants including key and general informants along with other multiple data sources (Morse, 1994).

Data Collection Process

This section illustrates an overview of how data was collected and highlights the particular issues encountered during the process of data collection. As it is a qualitative study, the researcher serves as the primary instrument to collect and analyze the data, moreover, self awareness of the researchers' role becomes essential. The researcher realizes what his role should be. The role is to participate in the culture, observe the participants, record observations, collect artifacts, interview members of the cultural group, analyze, and report the findings (Speziale & Carpenter, 2003). Therefore, documentation of the researcher's credential is essential in judging the worth of the study (Burn, 1988).

In this study, the researcher is an Indonesian who was born and grew up in Sundanese Muslim family. There are some advantages of doing ethnography study in the researchers' own culture, such as familiarity with the local culture and language of informants, which may help the researcher to understand the whole meaning and context of certain phenomenon. Access to informants and gaining trust from them is then easier since the Sundanese people are more likely to share their feelings and experiences with the one who comes from the same ethnicity. However, the possibility of missing relevant information may occur due to less sensitivity to nuances (Roper & Shapira, 2000). To overcome this issue, the researcher always needs to realize his role as researcher and doing reflection on prior assumptions. Such reflections were also conducted with a peer colleague who qualified in qualitative research to verify the research's findings. The researcher has been prepared to conduct a simple research since he was studying for his Bachelor degree in Nursing, and then, more advance research experience was obtained when completing his Master degree in Nursing. Apart of his position as a lecturer at Faculty of Nursing, a state University in Indonesia, he has been involved in a multi-disciplines research project and social activities concerning helping people with poverty-related infectious diseases, including HIV/AIDS. He also had participated in several seminars and workshops related to HIV/AIDS, both held in Indonesia and overseas. These provide the researcher with the advantage of a background which sensitized the researcher to pick up the culture care phenomena as a domain of inquiry in this study.

While studying in doctoral program, the researcher attended a course on the philosophical foundation and knowledge development in nursing, and conducted concept analysis on ‘concept of caring’ to understand the various meanings, attributes, antecedents, as well as consequences of caring. In addition, the researcher took a course and enthusiastically attended an advanced qualitative research in nursing which provided new knowledge of various philosophical and methodological approaches to the planned qualitative study. The researcher has conducted a pilot study as part of requirement to complete the course of seminar in doctoral thesis. It provided a real experience in gaining knowledge and skills of executing a qualitative study in a small test study.

As a part of completing the doctoral program, the researcher has conducted a mentorship program at the School of Nursing and Midwifery, Monash University, Australia. This provided a great experience to learn and share knowledge and skills related to research in nursing with the available outstanding faculties. These experiences were beneficial not only in gaining more knowledge and skills in data collection and analysis, but also increasing self-confidence to present the study findings to be more rigorous and trustworthy.

Commencing the journey

Upon completion of the research proposal and having been successfully examined by the Doctoral Program Thesis Committee of the Faculty of Nursing, Prince of Songkla University, to confirm the researcher’s candidature, the researcher went back to Bandung for collection the necessary data. As mentioned earlier, the researcher has been involved in a research project related to HIV/AIDS for about a year prior to enrolling in the doctoral program at June 2007. The project was organized under the Health Research Unit, Faculty of Medicine, Padjadjaran University, in collaboration with the Hasan Sadikin Hospital, the Radbound University at Nijmegen (The Netherlands), the University Antwerpen Belgium, and the University Maastricht (The Netherlands). The project is funded by The European Commission, and covers a period of five years (2006-2011). There were several benefits gained from being involved in such project, including access to PLWH, NGOs working for PLWH, and contacting community health centers, hospitals, and also local health authorities. Yet, the significant contributions were also gained from the various backgrounds of research peers such as in medicine, psychology, anthropology, public health, and education. As working and sharing with their experience in the field of HIV/AIDS, it would facilitate the researcher to better understand the current issues of HIV/AIDS care in Bandung.

Issues, such as using the term ‘research’ addressed to investigate a particular phenomenon related PLWH have become an intrusive term for several subjects as they may think that something would be taken from their body, such as blood sample, which might reveal their HIV status to other people. Some PLWH also felt being exploited while they were involved in research since they did not have any benefits from it. The researcher became more aware of these particular issues. As a consequence, building rapport and trust relationship in the initial steps of interaction with informants has been taken into account seriously. The benefit of this study was also highlighted the purpose of the project to improve the quality of community-based care for PLWH in Bandung, Indonesia. Eventually, since there was no prior study exploring Muslim cultural care for PLWH in Bandung, Indonesia, the study provided a vivid description that would lead to a better understanding about cultural care which was essential to develop culturally appropriate community-home-based care for people living with HIV infection in Indonesia.

According to the existing policy at the Bandung Municipality, everyone who would undertake research in or survey the community in the Bandung region, he or she has to have a legal permission from the Bureau of People Empowerment, Bandung Municipality. To comply with the policy, the researcher had therefore submitted all required documents to gain approval from the Bureau of People Empowerment at the Bandung Municipality. Two more approvals were obtained from the Head of the District Health Office at the Bandung Municipality, and from the Chairperson of the NGOs’ that assisted in getting access to the informants.

Getting access to the informants

The difference of people living with HIV infection compared to people with other diseases such as cancer or heart disease, is that they would not deliberately expose her/himself as PLWH as it carries a stigma. It have been cited in many previous studies that it might reveal stigma in the family, community, as well as in the health care setting (Kalichman et al., 2005; Merati et al., 2005; Paxton et al., 2005). Considering this issue, the researcher could not go directly to get the informant, since he was a stranger and outsider of the particular population. To gain familiarity with the informants' world, the researcher had to be involved in particular activities run by NGOs working for PLWH.

According to the data from the Bandung AIDS Control Commission (BACC, 2007), there were eleven NGOs recorded as providing support for PLWH. However, among those, there were only five that still sustain and actively coordinating with the BACC. Two of those were selected as the entry point of the study as they had a large coverage of PLWH, and over a much longer period than that of the other counterparts. The profile of the selected NGOs is described in the following descriptions:

The first NGO was the Bahtera Foundation *(Yayasan Bahtera)*. Its office is located in the Eastern part of Bandung City. When visiting Bahtera the first time, I was accepted by Mr. A, the program manager. He friendly explained the brief history, profile, working achievements, and management of Bahtera. He also welcomed me for doing research as it was beneficial for improving quality of care for PLWH. Bahtera was established in 1995 with the primary mission to contribute to community development and the protection of children. Since 2002, Bahtera has extended the program to outreaching for IDUs, HIV counseling, advocacy, and case management of IDUs and PLWH. The activities were funded by the Family Health International (FHI). Bahtera was acknowledged as the first and successful NGO in Bandung working on an outreach program for IDU. It has reached about 1000 IDUs since its start until June 2008.

Bahtera has also set-up a network with other stakeholders such as health official, community health centers, hospitals, prisons, police, schools, and other related-institutions. Bahtera was headed by a director, but when the visit was conducted, the leader was in the Aceh Province (the West most of Indonesia). To run the daily activities, there was a program manager who coordinated two case managers, four counselors, eleven field worker (outreach officers), one field coordinator, and five supporting staffs. Bahtera also organized official regular meetings including weekly staff meeting (for internal staff), monthly open meeting (for clients, families, and ones who interested), weekly close meeting (for clients only), and occasionally incidental meeting depending on demand. Apart from outreaching as the main program, the Bahtera also organized capacity-building trainings such as inviting experts to provide health education for clients as well as their family, motivation training for clients, community development, peer educators in prisons, and advocacy to policy makers and other related institutions. Outreach staffs were responsible to search and approach IDUs in particular areas of the community and persuade them to get VCT. Most of the outreach staffs were recruited from ex-IDU. Once a client was ready to get a test, he/she would be handled by a counselor who helps the client to understand the nature of HIV/AIDS, the result of the test (when they had a test), the consequences of either being HIV positive or negative, and also provide emotional support when the client encountered discomforting feelings.

If the client was HIV positive and/or need special care, the counselor referred to a case manager who would then be responsible to helping the client in order to get access to appropriate health care and be able to live well in community. The case manager usually conducted home visit to talk with client and to identify issues that need to be addressed, facilitating family to accept the client, advocacy to the community, and helping the client to get access to health care services as well as other community resources. Based on advice of the program manager, I might work closely with the case manager to get access to PLWH. However, to get insight into the entire activities of the Bahtera, I also was involved in other particular activities such as staff meeting, open meeting, close meeting, and capacity building. After understanding of how the Bahtera was going on, the researcher got intensively involved with the work of case manager. The researcher and the case manager sat together to identify a list of clients who potential could be recruited for the study. The case manager also provided a brief description about background, location, and the update information about the clients, and then making a schedule for conducting a home visit. On the first home visit, the researcher was escorted and introduced by the case manager to the client and its family. Normally, the first visit was aimed to make acquaintance and get an overview about the client condition. The following visits were made based on the permission of the client as well as of the family.

The second NGO was the Indonesian Family Planning Association *(Perkumpulan Keluarga Berencana Indonesia-PKBI)*. PKBI is a nationally leading NGO focused on family planning and women health. The central office of PKBI is located in Jakarta. PKBI West Java, which the researcher approached, is a provincial branch of the National PKBI. Although it is a branch, most of its authority in decision making and funding is in the PKBI West Java itself. The central organization only acts as coordinator and supervisor for the program. PKBI is well-established and has its own building secretariat supported by the local government. The secretariat of

PKBI West Java is located in Eastern part of Bandung City, and has been running since 2004. Most of the programs run by PKBI West Java are supported by the Family Health International. Initially, the PKBI West Java focused on STDs particularly among commercial sex workers. Since 2006, PKBI West Java has extended the coverage not only to STDs but also to HIV among CSWs, CSWs' clients, IDUs, and transgender *(waria)*. There are five areas of PKBI's coverage namely HIV/AIDS, adolescent reproductive health, access to service for marginal population, advocacy, and 'save abortion'. PKBI West Java is an NGO that offers VCT, STD clinic, and simple laboratory support for both stations as well as a mobile clinic service. Until 2007, PKBI West Java had provided VCT to around 1400 clients. The average client visit to the clinic is about 150 – 200 persons/month, most of them are from high-risk groups. During 2006, it found around 5 HIV cases daily. Besides station clinic, PKBI West Java also offers mobile clinic 4-5 times/ month to reach people of risk groups who could not come to the clinic such as those working in massage parlors, bars, and prostitutes, etc. The PKBI West Java clinic is situated in the center of Bandung City, next to the main prostitution area, yet since the local government prohibited prostitution in 2006, the CSWs who previously visited the clinic regularly, gradually disappeared, probably they moving to other places and lossing contact with the clinic.

A similar approach to get access to PLWH was applied to PKBI West Java. Initial meeting with the program manager and the branch chief of PKBI West Java was conducted. However, the researcher did not involve in all large coverage activities of PKBI West Java due to time limitation. He worked closely with the case manager who manages HIV-positive clients referred by the clinic and/or the counselor. The first contact with informants was made through mediation of the case manager, and the following home visits were made on the basis of clients' permission. At that time, the researcher did not consider to gain access through nurses in hospital clinics because observation and inputs from colleagues suggested that the NGOs is a good point to facilitate access to PLWH since they have worked more closely with the PLWH in communities rather than do nurses.

Exposing researcher values

During the course of research the researcher continuously evaluated his expectations and personal values that may interfere with the data. For example, an informant eloquently expressed how difficult it is to see a doctor in the HIV/AIDS Clinic just to get the ARV medication. Feeling empathy to the informant and prejudice to the behavior of the health care provider arose in the researcher's mind. The researcher attempted to locate this feeling in the memo and looked for further clarification from the health care provider. The researcher's self-reflection in memos and discussions with advisors throughout the course of the study helped him to identify the interference of his assumption to the study. Reports of fieldwork progress and asking for feedback and comments were sent monthly to the advisors in Thailand. In addition, by the end of each semester (4 months) of the study the researcher traveled to Thailand and presenting the data in a peer of PhD Student as well as to the PhD thesis committee to report the progress, asking for comments and suggestions and discussing particular issues encountered during fieldwork.

Leaving the field

The process of leaving the field was conducted gradually. The researcher informed the informants in advance that the researcher's field work would cease after reaching sufficient data. However, keeping in contact by phone or email was offered to informants in case the informants needed to clarify the data. Some informants expressed their expectancy to the researcher to be able to assist in developing their self-help group program. The researcher was aware that they have developed trust and probably viewed the researcher as a kind of resource to solve their problems. The researcher honestly told them that in the context of the present study it was quite hard to fulfill their expectancy. However, it was not impossible after completing the study, the researcher would come back as a friend and would assist them something as much as he was able to do. The researcher valued their high expectancy as a sign of good trust in the relationship. However, many things in this present life need to be realistic in order to minimize feelings of frustration as a result of failing to achieve the too high expectancy.

Data Collection Methods

The ethnonursing method focuses on describing the culture of care as a nursing phenomenon which aims to gain a better understanding of the phenomena to improve the quality of nursing care. In practice, the method embraces various techniques of data collection that similar to ethnography. The principal methods of data collection used in this study involved participant observation, interviewing, focus group discussions, and examination of available documents. These techniques were able to provide a rich source of data on which a vivid description of the phenomenon of Muslim cultural care for PLWH in the Bandung Community Indonesia, could be developed.

Participant observation

In ethnographic studies, participant observation is the major method of data collection (de Laine, 1997). Participant observation allows the researcher to capture the informant’s point of view during the interaction process. Becker and Geer (cited in Roper & Shapira, 2000) described participant observation as gathering data by participating in the daily life of a group or organization. Since the role of the researcher is important, the Leininger’s observation-participation-reflection guide was used. It helped this researcher to enter and remain with informants in the familiar or natural cultural context while doing the study and changing his role from a non-participant observer and listener to a real participant and reflector for the informants. This whole process consists of four phases: (1) primarily observation and active listening, (2) primarily observation with limited participation, (3) primarily participation with continued observations, and (4) primarily reflection and reconfirmation of findings. The researcher and the informants clarified what things that have been shared or explained. Being an active observer, listener, and reflector is crucial to ethnonursing research method while focusing on the domain of inquiry (Leininger, 2002a).

Three types of observation were the main methods in this study; descriptive observation, focused observation, and selective observation (Spradley, 1980). Descriptive observation was used to get information about general situations, especially at the initial process of the study, and includes space, actors, activities, objects, time, goal and feelings that appear in the study setting. Focused observation was conducted to gain information about particular issues that come up from the data through analysis process. Selective observation was added after data analysis and repeated observation to gain more data related to particular situations or issues that seemed important to deeply understand the phenomena under study.

As a participant-observer in fieldwork, there are several roles which the researcher may adopt through the course of the study, depending on the setting provided. For the purpose of the present study, the descriptive observation took place in several stages. First, whilst the researcher initially visited the NGOs to gain approval of the head of NGOs, and being involved in particular activities of the NGOs, second, as the researcher firstly conducted a home visit, and third, as the researcher escorted the informant to a health care setting. These observations were made unstructured. The researcher entered the field with a broad view, which involved looking at events, activities, and cultural aspects of the informant’s behavior. The researcher entered the NGO’s office, informant’s house, or a clinic with an open mind and without expectations, just to see the real nature of these settings. In the NGO’s office, the researcher observed how each staff member performed its job according to the job description, how the staff members organized meetings, and how they interacted among each others. Focused observations were conducted particularly when the staffs approached and handled their clients. In the house of the informants, the descriptive observations were addressed to see the overall life condition of the informants, such as housing (exterior and interior), air ventilation, lighting, number of family member, the main daily activities of informants, and how they interacted with their family and community. Specific issues were observed such as how they handled a particular health problem, and how the family care giver provided care for the informant while sick. In addition, selective observations were primarily made of some informants who encountered specific conditions in which care phenomena became more apparent such us while an informant was admitted to hospital, or in a dying condition. The researcher engaged initially in general observations of the setting until familiar with the rhythms and patterns of the NGOs, the house of the informants, and the HIV/AIDS clinic.

The observation guide was made for focused and selective observation to anticipate missing of essential data. Field notes were generated from all types of observation and completely record at the same day the researcher had left the settings. Once the researcher felt he had established rapport with the key informants, the informants were willing to deeply express their feelings and share their experiences related to living-with, and care-for HIV/AIDS. Along the course of field work study which lasted eight months (June 2008 to January 2009), the researcher has conducted over 36 times home visit to the twelve key informants. Each informant was visited at least two times and the length of a visit was about one to two hours.

Figure 4 Participate in PLWH group meetings

Conversation and interviews

Conversation related to the study actually was begun since the researcher conducting a peer review about study proposal as well as for research questions. Similarly, conversation or unstructured interviews also were conducted with the program managers, family care giver, NGOs' staffs, and health care provider in the HIV clinic. These were done to gain more understanding about current situation regarding HIV/AIDS in Bandung City. After obtaining a clear picture about the current situation of HIV/AIDS and its prevention, care, and treatment in Bandung, the researcher began to identify key informants to be interviewed.

Selection of the key informant was made based on purposive sampling, as it is recommended by many authors (Denzin & Lincoln, 2000; Lincoln & Guba, 1985; Marshall & Rossman, 1999). Informants were selected on the basis of considerations, those who were more knowledgeable, having a rich experience, and were willing to participate in the study. The researcher then invited those informants to participate in the study. A verbal explanation outlining the study was given to the informants in plain language according to informants' language preference (Sundanese or Bahasa Indonesia). The information included the purpose and benefits of the study and informants' roles and confidentiality of the data. An interview was conducted after the researcher had established rapport and a trust relationship with the informant. The researcher asked agreement of the informant in choosing a time and place convenient to both the researcher and the informants to conduct an audio-taped interview. Follow up communication by phone was made to appoint for additional meeting or interview. The interview guide was used to assure the conversations were on the track of the research inquiry. Spradley (1979) suggested the researcher to think of ethnographic interviews as a series of friendly conversations into which the researcher slowly introduces new elements to assist the informants to respond as informants. The initial question was started with broad descriptive question such as “How is your daily life going on?” Structured and contrast questions were asked to explore much more deeply the specific issues of Muslim cultural care for PLWH. During the interview, the researcher encouraged the informant to clarify and elaborate the details of his/her experience by using probes or focused questions such as “What does it mean to you?”, or “What does make you think like that?” The informants were asked to respond to the questions in as much detail as they feel appropriate. In addition, the researcher asked for clarification and reflection and asked more detail if it seemed necessary.

The researcher kept interviewing informants until reaching the stage whom no new information emerged by conducting additional interviews. The information was considered as sufficient when no more new information could be elucidated by the informant. In another words, sufficient data was acquired when the saturation stage was reached. Without meeting the criteria of saturation, qualitative results are thin and the reliability and validity of the studies can be questioned (Morse & Field, 1996; Seidman, 1998). Along the course of field work, twelve key informants, eight family caregiver informants, and two community informants have been interviewed in-depth. Interviews lasted from 45 minutes to 1.5 hour and were audio-taped. Occasionally, an interview was conducted together between key and general informants, otherwise individually interviews were taken to confirm particular issues that could not be expressed by either key or general informants in front of each other.


[redacted] [redacted]

Figure 5 Interview with a family caregiver

Focus group discussions

Most researchers in qualitative research rely on the two major techniques to collect data, namely participant observation and individual interviews (Madriz, 2003). However, in some instances, the researcher wishes to gather information from a particular group while individual interviews were considered to take too much time. For this reason, focus group discussion can be a suitable technique. Leedy and Ormrod (2009) highlighted that focus groups are especially useful when there are specific conditions such as time limitation, or people feel more comfortable talking in a group than alone, and interactions among participants may be more informative than in individually conducted interviews. As a technique of gathering data, focus groups have limitation in explicating a range of behavioral information since focus groups meetings mostly taking place outside of the setting where social interaction typically occurs. However, focus groups may allow the researcher to observe the interactive processes which occur among participants, and that sometimes these include spontaneous responses from the participants, and also enable researcher to gather a large amount of information in a limited time. To conduct a focus group, the researcher usually gathers several people (8-12) to discuss a particular issue for 1-2 hours. A moderator (who may or may not be the researcher) introduces the issue to be discussed and in managing the group discussion to keep focus on the topic and no one can extremely dominant or silence (Leedy & Ormrod, 2009).

In this study, two focus group discussions were carried out to gather supplementary data about caring for PLWH from the health care providers' and community leaders' perspectives. The first group, health care providers who were taking care of HIV/AIDS patients, was invited to discuss particular issues related to caring for HIV positive patients. Nine participants (2 physicians, 1 HIV counselor, 2 community nurses, 2 nurses from HIV clinic, and 2 nurses from hospital wards) attended the meeting and were enthusiastically discussing the issues arisen by the moderator, which was the researcher. The second group consisted of community leaders who were invited from a sub-district area of Bandung. The group of seven persons consisted of one religious leader, one deputy village head man, two neighborhood leaders, one village health volunteer *(kader kesehatan)*, and two persons from village youth organization.

The researcher opened the session by welcoming all participants and appreciated their attendance. Each participant was given the chance to introduce him/herself and give his/her brief background. A clear explanation about the purpose and benefits of the study including the contribution of participants was provided. In order to make discussion more lively, the researcher encouraged each participants to freely express their feelings, opinions, and knowledge without hesitation and feeling intimidated. All given information was kept confidential and used for the study purpose only and all participants were asked to maintain confidentiality outside the group. Questions used in the focus group had been previously developed by the researcher and were reviewed by the researcher's advisors. Each group initially discussed the perception toward PLWH. Then, the health care provider group was asked what they thought that health care providers had done well and not well in caring for HIV/AIDS patients. Specific issues were then raised by the moderator if necessary, such as the encountered barriers in care for those patients, how they coped and identified any particular beliefs, values, or practices that reflected cultural care.

The community key person group was further asked what they supposed to do when they found a community member was known as HIV infected. Specific issues such as the role of community in prevention and care for HIV/AIDS as well as cultural beliefs and practices related to prevention and care for HIV/AIDS were addressed in the discussion. During the introduction process, most participants spontaneously offered their opinion toward HIV/AIDS and PLWH. In the further process, some questions were modified, or additional questions were asked on the basis of a previous session. At the end of the session, the moderator and assistant-moderator reviewed the common perceptions and opinions expressed in the groups for confirmation. To appreciate, meals and refreshments were also provided and each participant received a proper transportation fee for attendance. All conversations within the group were audio taped and transcribed. Written notes from the note-taker were then reviewed and combined. Each focus group discussion lasted from one to two hours.


[redacted] [redacted] [redacted] [redacted] [redacted]

Figure 6 focus group discussions with community leaders

Examination available documents

The process of ethnography is a holistic appraisal of the lifeways of a population, knowledge about past events, and changes over time which helps to locate and understand the present (Germain cited in Roper & Shapira, 2000). Relevant information may be included in written documents such as patient records, policies and procedures, education materials, newspaper articles, fact sheets, or official reports from local and national government as well as international agencies. Data found in written archives or spoken life-histories of participants may reveal historical underpinnings of current events. However, the researcher is advised to see documents as social products that need to be critically examined as a research resource (de Laine, 1997). Investigation of the contexts of official documents and their usage can provide useful indications to raise further questions regarding phenomena being inquired.

Along the course of field work, the researcher was able to collect a series of documents from key informants, NGOs, health care settings, Bandung Municipality AIDS Commission, District Health Office of Bandung City, Ministry of Health, National AIDS Commission, USAID, AUSAID, WHO, and UNAIDS. Some documents needed permission to be obtained while others were available in the public domain. Document from key informants included patients' card presenting medical record number, tracks of patients' follow up, and anti-retroviral medication, and also some brochures related to HIV/AIDS. NGOs' documents included organizational structure, job description, and work program. Manual practice for care and treatment of HIV/AIDS, standard patient care, and health teaching materials were collected from community health care settings. Official documents included annual reports, epidemic updates, fact sheets, health profile, National Action Plan, and strategic planning for HIV/AIDS control and prevention. Some information was cited to provide an overview about HIV/AIDS epidemic in Bandung-West Java-Indonesia, and describe the context of the study.

Instruments

The instruments for data collection including the researcher, personal information form, interview guide, observation guide and Leininger's observation-participation-reflection guide, field notes taking form, Leininger's "stranger to trusted friend guide", camera, and audiotape recorder.

1. The researcher

In a qualitative study, the researcher serves as the primary instrument to collect and analyze the data, moreover, self awareness of the researchers' role is essential. Because the researcher becomes the instrument, the researcher must realize of what the role of instruments entails. The role is to participate in the culture, observe the participants, document observations, collect artifacts, interview members of the cultural group, analyze, and report the findings (Speziale & Carpenter, 2003). In doing so, a high level of intellectual discipline is required. Therefore, documentation of the researcher's credential is valuable in judging the worth of the study (Burn, 1988). Documentation of the researcher background has been provided earlier in the data collection process.

2. Personal information form

A personal information form was designed to obtain personal information characteristic of key and general informants (Appendix A, B, and C). This information was useful to provide the contextual background of informants that may link to their caring experience and/or expression.

3. Interview guide

An interview guide was developed by the researcher as a primarily guide for interviewing the informants (Appendix D). After establishing a trust relationship, the interview guide was used throughout the fieldwork with the informants. Spradley (1979) suggested the researcher to think of ethnographic interviews as a series of friendly conversations into which the researcher slowly introduces new elements to assist the informants to respond as informants.

4. Observation guide

In this study, the researcher conducted three types of observation; descriptive observation, focused observation, and selective observation (Spradley, 1980). Descriptive observation was used to get information about general situation, especially at the initial process of the study. Focused observations was conducted to gain information about particular issues that come up from data analyzed, for example, how an informant interacted with a nurse in the context caring relationship.

Selective observation was determined after more data was analyzed and whether repeated observation to gain more data related to a particular situation or issue was important to deeply understand the phenomena under study. A general observation guide was prepared to help the researcher to document “what is going on in the setting of the study?” It included space, actors, activities, objects, time, goal and feelings that appear in the study setting (Appendix E.1). Leininger’s observation-participation-reflection guide helped the researcher to enter and remain with informants in the familiar or natural cultural context while doing the study and move from observer and listener role to gradually a participant and reflector role with the informants. This guide consists of four phases: (1) primarily observation and active listening, (2) primarily observation with limited participation, (3) primarily participation with continued observations, and (4) primarily reflection and reconfirmation of findings (Appendix E.2). The researcher and the informants clarified what they have shared or explained. Being an active observer, listener, and reflector is crucial to the ethnonursing research method, while keeping focused on the domain of inquiry (Leininger, 2002a).

5. Field notes

Field notes taking forms (Appendix F) was designed to document the researcher observation as an additional form to general observation. The notes included what the researcher heard, see, think, and experience in particular situations or events which incorporate theoretical, methodological, and personal researcher view points.

6. Leininger's stranger to trusted friend guide

This guideline helped the researcher evaluate the moving of the role from a stranger role to a friend role to obtain accurate, sensitive, meaningful, and credible data (Appendix G). This guide was designed based on the philosophical belief that the researcher should always evaluate and measure the relationship between researcher and people being studied in order to get close to the people or to the situation under study. It is considered that by using this guideline, the researcher was able to obtain accurate and credible data throughout the ethnonursing research process.

7. Camera

A camera was used for taking photographs of particular events or objects which provide meaningful data.

8. Audiotape recorder

To prevent missing some important information during an interview, upon permission of interviewed persons, the interviews have been audiotaped.

Data Analysis

Data analysis in qualitative sense has been known as an 'iterative' process which involves repetition from the first observations in the field, developing a classification system to put issues and concerns into categories of analysis, and verification of meaningfulness and accuracy the data (de Laine, 1997). The researcher often needs to go back and forth while developing a classification system to bring sense in explaining what the researcher has learned during the research. Analyzing data in ethnographic studies is a lengthy, complex and time consuming activity, begining in the field while data are being collected, and requires specific methodological strategies to verify data and validate conclusions (Miles & Huberman, 1994; Roper & Shapira, 2000). Many researchers have introduced methodological strategies or guidelines to analyze ethnographic data such as Spradley (1979), Leininger (1985), de Laine (1997), Roper and Shapira (2000), and Richard (2005). None of the guidelines are precisely alike. There is no clear rule to guide a novice researcher to use a specific guideline in analyzing data rather than depending on the purpose of study and the research questions to be addressed. However, there are some similarities among the existing data analysis guidelines as highlighted by Miles and Huberman (1994) in that the process of data analysis basically includes data reduction, data display, drawing conclusion and verification.

The huge challenge for the researcher is to reduce the data into categories and concepts and develop a frame work to communicate central ideas of research findings. The researcher collects copious amounts of notes about what the informants do, what the informants say in interviews or group discussions, what available relevant documents tell, and the researcher’s personal reflections during field work as well as analyzing data. Therefore, all data need to be reduced by selecting, focusing, abstracting, and transforming them into concepts and categories. All data were analyzed as they were collected and preliminary analysis was done on a daily basis. Figure 7 illustrated the process of data management and analysis. The process of data analysis in this study involved four steps as recommended by Leininger (2002a):

1. Collecting, describing, and documenting raw data

In this phase, the researcher began to collect data related to caring and cultural aspects of care for people living HIV infection. Data were obtained through participatory observation while family caregivers and health care providers cared for those people. Field notes were abstracted from the field observation. Personal as well as group interviews were made to gain insight about perceptions, meanings, and experiences related to Muslim cultural care for PLWH. The interviews were tape-recorded upon permission of informants. All data recorded and were immediately stored in a secured personal computer. The interviews were transcribed and carefully checked for accuracy and consistency. The researcher read and re-read all data to get familiar with the whole picture of the situation. This was then validated with the other source of data related to the caring situation. The data collected focused mainly on emic rather than etic perspectives. The data were then preliminary interpreted and identified on keywords to understand the contextual meaning.

2. Identification and categorization of descriptors and components

Data were coded and classified into categories in relation to research questions. It included perception about HIV and AIDS and living with HIV/AIDS, meanings of caring and self-care activities of PLWH, care and supports for PLWH provided by family caregivers, health care providers, and community, and cultural values and beliefs associated with caring for PLWH. Data descriptors related to each category were studied to identify similarities and differences. Recurrent components were studied for understanding of their meaning. For example, when the informants frequently expressed that they had to accept the reality of having HIV infection as a form of caring for themselves. It was then confirmed by other data related to the meaning of caring as accepting the reality of having the HIV infection.

3. Pattern and contextual analysis

In this phase, data were scrutinized to discover saturated ideas and recurrent patterns of similar or different meanings, expressions, structural forms, interpretations, or explanations of data related to caring for PLWH. Data were examined to identify recurrent patterns in responses to the words HIV and AIDS or care with respect to meanings and contexts. The researcher brought the preliminary results and discussed with the informants to offer them a chance that the researcher's interpretation were in accord with the informants' view as revealed in the data. To provide contextual meaning, the researcher described observations that had been occurred during data collection which included the meanings that emerged from the exercise of research findings. For example, when an informant said he or she feel embarrassed if people know his/her HIV status, they would like keep it secret. The researcher observed the non-verbal expressions, such as lowering speaking voice, and eyes' looking at outside through the window, that might support the meaning "living with HIV infection as shadowed by feeling of embarrassment".

4. Major themes, formulation research findings

This is the highest phase of data analysis, namely synthesis and interpretation. The researcher synthesized his thinking and interpreted the data. Then, he abstracted, identified, and presented major themes from the patterns that emerged from the data related to Muslim cultural care for PLWH. Covert and overt factors related to the cultural aspect of caring for PLWH were identified and followed by a secondary review of all data. Eventually, cultural understanding with regard to Muslim cultural care was drawn and described to explain cultural care for PLWH. For example, perception about living with HIV/AIDS as a test of faith and patience, reflects Islamic beliefs on illness, hunger, and pain in the present life as a test to proof the faith of human beings toward their Lord. If they can pass the test, they will be blessed to enter paradise in the hereafter life.

Trustworthiness

Trustworthiness refers to the reliability and validity of a study findings (Lincoln & Guba, 1985). The findings of this study were evaluated by a process including credibility, confirmability, meaning-in-context, recurrent patterning, saturation, and transferability (Leininger, 2002a). The procedures to ensure trustworthiness in this study are described as follows.

1. Credibility

Credibility refers to the “truth”, accuracy, or believability of findings that have been mutually established between the researcher and the informants. The activities in the field include prolonged engagement, persistent observation, triangulation, peer debriefing, and member checks as recommended by Lincoln and Guba (1985) to increase the chance of high credibility. In this study, the researcher has spent eight months in the field to build relationship and trust, by participating in the daily life of informants as well as in NGOs’ support group activities for PLWH. To avoid the phenomenon of “going native” which refers to a possible loss of academic credibility due to long engagement with the informants (Lincoln & Guba, 1985), the researcher maintained awareness of this issue by stepping backward from the field for temporary and locating his point of view in a memo, separated the view with the informants’ point of view. Data were collected by using the multiple methods including participant observations, interviews, and focus group discussions to meet criteria of triangulation. Member checking has been assured by presenting findings and interpretations to representatives of the informants from which the data were collected and gathering feedback regarding the authenticity of the data and researchers' interpretation (Leininger, 2002a). Member checking can serve to facilitate rapport, acceptability, and participant 'ownership' of an intervention through the involvement of data interpretation and use. Findings and interpretations were confirmed with some informants to take account of findings of the study. Since the researcher is from the same culture, it was beneficial to facilitate and shorten the period of building rapport with the informants.

2. Confirmability

Confirmability refers to the documented verbatim statements and direct observational evidence from informants, situations, and other people who firmly and knowingly confirm and substantiate the findings (Leininger, 2002a). To meet this criterion, the researcher restated the ideas or findings that he has heard, seen, or experienced with key informants and some general informants. This was done when a particular issue was unclear. For example, the issue of having HIV as an "*aib*" (disgrace) that should be covered, it need to be confirmed by religious leader informants who knowledgeable about this issue. The process in this study was presented in detail in order to provide a clear account of the methodological decisions taken in the course of the project. Raw data were systematically recorded and noted. Audiotapes, transcripts, and data analysis products were arranged and sorted. Field notes were recorded on a regular basis. All the steps of data collection and data analysis were carried out under the supervision of research advisors. They performed an audit to confirm the researcher’s raw data and also in each step taken during data collection and data analysis were suitable and whether interpretations were made appropriately.

3. Meaning-in-context

Meaning-in-context refers to understandable and meaningful findings that are known and held relevant to the people within their natural living environmental context and the culture (Leininger, 2002a). This criterion focuses on the significance of interpretations and understanding of the actions, symbols, events, communication, and other human activities within specific or total contexts in which something occurred. In this study, the researcher combined the data from interviews, observations, and documents to interpret and understand their meaning, which then were confirmed by all key informants and some general informants. All of the data were linked to the environment and the contextual realities. For example, the notion of caring as performing an optimal effort and supplication, could be meaningless unless proven by the real actions to maintain health, such as adhering to taking ARV medication timely, which can be confirmed by the patients’ medication card.

4. Recurrent patterning

Recurrent patterning refers to documented evidence of repeated patterns, themes, and acts over time reflecting consistency in lifeways or behavior patterns (Leininger, 2002a). To meet this criterion, the researcher used repeated experiences, expressions, events, or activities of informants in relation with Muslim cultural care for people living with HIV/AIDS to identify the patterns of caring. For example, the practice of cleanliness emerged repeatedly both in informants’ narration and in their behavior, which reflect habitual action that could be extracted as a theme.

5. Saturation

Saturation refers to in-depth information of all data and that there was no new data or insight coming forth from informants or observed situations. This criterion was met when the collected data revealed redundancies or duplication of content with regard to similar ideas, meanings, experiences, descriptions, and other expressions from informants or repeated observations. This was considered to be inferred when the data has reaches the saturation point. For example, when the researcher inquired repeatedly about the informants' perception about HIV and AIDS, and there was no new contrast theme coming out apart from the four themes found in this study, namely: deadly illness, dirty illness, horrifying illness, and young people illness.

6. Transferability

Transferability refers to whether the findings from a complete study have similar (not necessarily identical) meanings and relevance to be transferred to another, but similar situation, context, or culture (Leininger, 2002a). In order to meet this criterion, the findings of the study were reported in a rich literary style. The report included quotations, commentaries, and stories which add to the richness of the report and to understanding the context of experience in which it all occurred. The researcher facilitated transferability by providing detailed documentation in all phases of the study, while decisions about transferability were considered as the readers' responsibility when they intended to apply the findings in other contexts (Lincoln & Guba, 1985). For example, perception of living with HIV infection as a test of faith and patience is applicable onto other PLWH who have similar beliefs in other settings.

Translation Issue

As the research proposal, the interview, and the observation guide were written in English, the proposal and the guide were translated into Indonesia Language *(Bahasa Indonesia)* to be able to be used in the setting. Two bilingual colleagues were asked to review those and give inputs and suggestions for improving the translation version.

During data collection, informants were interviewed either in the local language *(Sundanese)* or in *Bahasa Indonesia*. Informants who speak Sundanese were recorded and transcribed into *Bahasa Indonesia*. Furthermore, the researcher translated all that into English. The process of transcribing and translation was very difficult and time consuming due to the language barrier and several cultural differences. To verify the accuracy of meaning and context of certain terms or phrases, the researcher asked an Indonesian English teacher to check and present suggestions.

Ethical Consideration

Permission for the involvement of participants was obtained from the Institutional Research Board Committee, Faculty of Nursing, Prince of Songkla University and from the Local Research Authority in Bandung (Appendix H). 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 allowed to ask questions and to decline or accept participation in this study or withdraw from the study at any time they wish. Either verbal or written informed consent was offered to each informant before beginning with the interviews (Appendix I).

To prevent harm, suspicion, or risk of disclosure of the informants' HIV status during home visits by the researcher, the visits were scheduled based on the key informants' convenience as to time and conditions. In the first visit, the researcher was usually accompanied by an NGO staff that was already known to the family members or even to some neighbors of the informants. As to female informants who are wives infected by husband, the researcher came with one or more female NGO staff. At the next visits, the researcher occasionally came alone or with a team of NGOs. In case of an interview with a female informant, at least one family member stayed. This is important in Muslim culture to avoid of being gossiped or negatively imaged from surrounding people when a man and a woman who are not in family bounding sit and chat together in a private place. If anyone inquired about the purpose of visits, the researcher informed him/her that the researcher was conducting a research project to understand how a sick person experiences his/her illness and how family and community took care for him/her at home or in the community. The general term such as "chronic illness" instead of specific indicated the disease was used when being asked by others. The HIV/AIDS status of the informants was thus kept confidential.

The confidentiality was assigned to each of the participants. All the personal identifiable information was maintained in confidence throughout the research and thereafter. All data gathered in this study, including the audio-tapes and transcriptions, field notes, and computer files were kept confidential and stored in a secure place.

The researcher informed the informants that raw data would only be available to the researcher and his advisors, the anonymity of informants was ensured by using codes for all data sources. The results of the study were presented in group-form and no information could be used by individuals to identify anybody. The informants' photographs were only presented in groups and their faces were covered.

Summary

The ethnonursing method was used to carry out this study which took place in Bandung, West Java Province, Indonesia. Data were collected from both the key informants and the general informants by using the instruments including the researcher, the interview guide, Leininger's observation-participation-reflection guide, field-notes taking form, camera, and audiotape recorder. Data collection and analysis were conducted simultaneously. Data gathered from interviews were transcribed verbatim and fed into a secured personal computer. The process of data management and analysis involved the steps as illustrated in the figure 3. Ethical approval was obtained from the IRB, Faculty of Nursing, Prince of Songkla University. The findings of this study were evaluated for trustworthiness by a process including credibility, confirmability, meaning-in-context, recurrent patterning, saturation, and transferability.

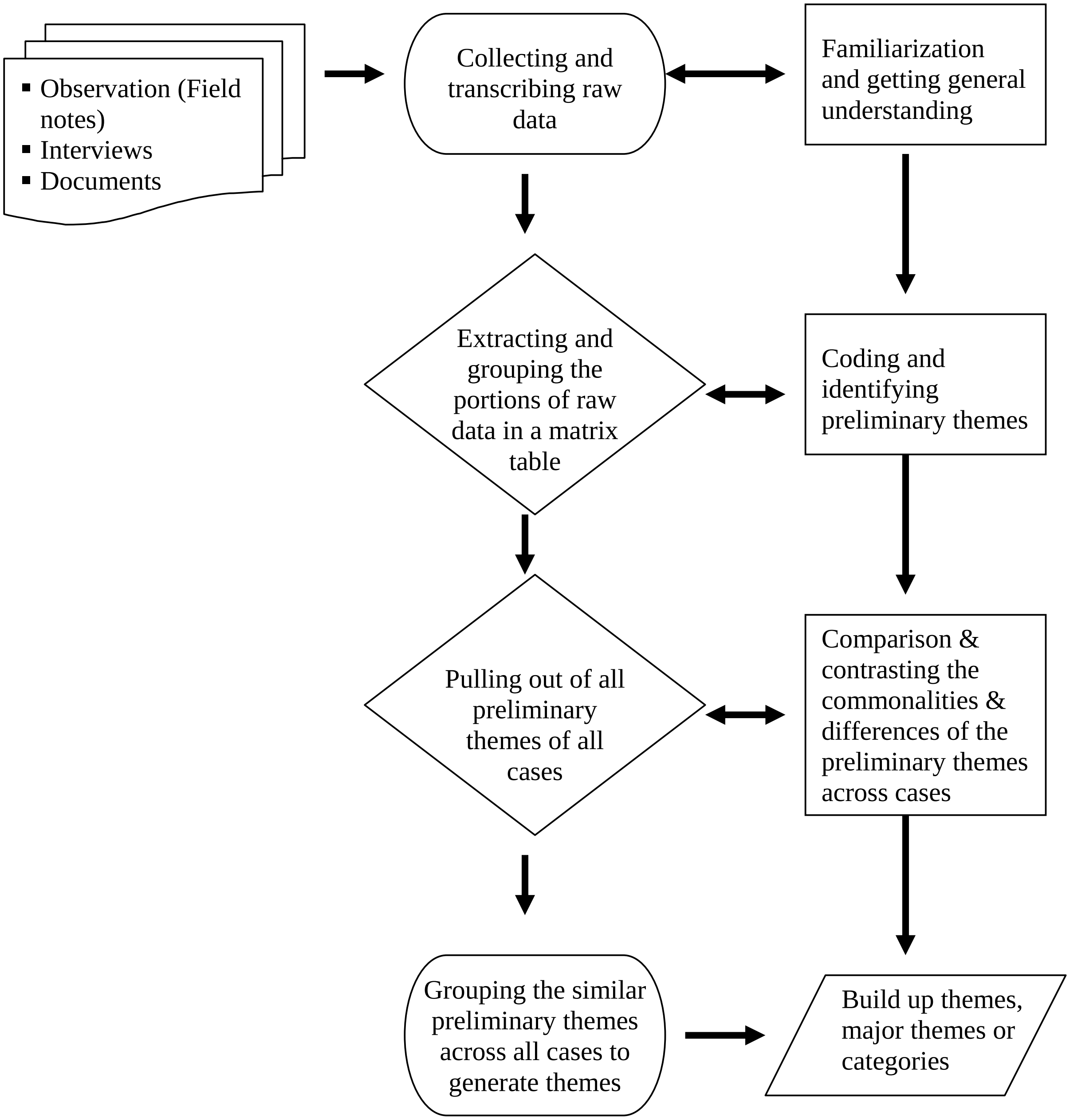


Figure 7 The flow diagram of data management and data analysis

CHAPTER 4

FINDINGS AND DISCUSSION

This chapter presents the research findings and discussion related to cultural care for people living HIV infection in the cultural context of a Muslim community, as derived from the ethnonursing research method. The findings come from the *emic* perspectives or insider’s experience of the PLWH and related carer in Bandung, Indonesia. This chapter starts by describing the characteristics of the key and the general informants, followed by depicting descriptors and patterns related to perceptions about HIV and AIDS, and living with HIV infection; the meanings of caring and self-care activities of persons living with HIV infection; care and supports for PLWH provided by the family, the health care providers, and the community; and cultural beliefs and values associated with caring for PLWH in a typical Muslim community. A discussion on research findings ends this chapter.

Characteristics of Informants

Characteristics of key informants

Key informants were twelve persons who had been diagnosed as HIV positive and who knew their HIV status. The real names of the informants are substituted by codes K1 to K12, which refer to those key informants. During the data collection phase of this study 2 informants died due to lethal complications from having AIDS. The characteristics of the informants are described as follow:

K1

K1 is a 33 years old male, who completed junior high school. He was an IDU for about eight years (1997-2005). By the end of 2005 he stopped using drugs when he was aware that most of his friends who used drugs had died and when his drugs supplier was arrested by the police. K1 is a Sundanese man who identified himself as a Muslim. K1 has known his HIV status since September 2007. From the end of 2005 to 2007, his health deteriorated. He experienced a dramatic body weight loss and showed signs and symptoms indicative of skin herpes, diarrhea, chronic cough, and fatigue. He commenced an HIV test in a Public Hospital where he was informed that he was HIV-positive. K1 indicated that he was re-admitted to hospital because of persistent diarrhea, chronic cough, and the inability to eat, which led to weight loss after one month from the HIV test. He was hospitalized for about one month and received anti tuberculosis medications. Currently, he lives with his 22-years wife, his 2.5-years son, and his mother who in 53 years old. His wife was tested with an NGO, the result was positive with CD4-cells count of 600/mm^3. Their son had not been tested at the time of data collection. K1 defended his decision not to have his son tested stating he looks healthy, is too young and is scared of needles. K1 and his family have been living in his mother’s house since being discharged from hospital. His mother is employed in a local garment factory and financially supports K1, his wife and their son. K1 is unable to work and spends most of the time in his house in an ongoing attempt to recover his health. Before, he used to work as self employed without regular income. Occasionally, he goes out to have a light physical exercise, looking for a livelihood, and to release the feeling of being bored of staying at home the day after day.

K1 appeared quite healthy at the time he was interviewed for this study. He expressed that his health status was improving as a result of taking medication, although he complained of feeling fatigued, having numbness in both legs, of skin irritation, and of the enlargement of his breasts which he understood was a side effect of the anti-retroviral medication. A month ago his CD4-cells count was 600/mm^3. The medication regime he explained included ethambutol once a day, INH once a day, ciprofloxacin twice a day, efavirenz once a day, stavudine twice a day, and hiviral (lamivudine) one a day.

K2

K2 is a 38 years old female who completed senior high school. She has been married twice and both husbands died. K2 has two daughters, the oldest being 7 years is from the first husband, who died because of heart disease, and the second being 1.5 years is from the second husband, who died of AIDS related complications. Her second husband was a former drug-user for a long time and stopped using drugs for about five years before marrying her. Therefore, K2 was willing to receive him to be her husband. However, her husband while living with her, still was heavily addicted smoking and drinking coffee. Then, a year after they married, her husband’s health condition became poor. His body weight dropped and he had persistent diarrhea and respiratory problems. He was taken to hospital and admitted for a week. Being home from then on, he eventually died on October 2007 with diagnosis of AIDS, as then it was too late to get proper treatment for him. Shortly, after knowing that her husband had AIDS, her niece who worked in a pharmacy shop brought her for a test to a private laboratory. She was shocked, sad, and depressed, when she learned that she was also infected by HIV. She did nothing for about six months after testing until she felt something wrong with her body. Her skin was erupted and had many lesions. Her body weight decreased dramatically. She described it as ‘I was like an old women’. She did not go to hospital because of lacking the money. After several months, a relative, who worked in the Social Office, took her to a hospital and helped her being accepted in the ‘government health insurance for poor people’. After being admitting in hospital and receiving anti-tuberculosis therapy for several days, she was discharged from hospital and went to stay in her mother’s house. She completed a course of TB treatment for nine months, and then took anti-retroviral therapy. She experienced weakness, nausea, headache, and discomfort for about three days after taking the ARV. During the time she lived with her mother who cared for her. Later on, her mother passed away and she decided to stay with her oldest sister who lived in an adjacent neighborhood as did her mother. Her oldest sister is also a widow and is fully supported by her children for running her household.

When the interview was conducted, K2 looked healthy, energetic, and cheerful, and was able to communicate very well. She is ethnically Sundanese and Muslim. She accepted to take care of her daughters and her small nieces. She has no serious complains regarding her physical condition. She verbally expressed happiness with her health and her body weight, which improved becoming better, even as she was well aware of her HIV status has already lasted for about one year. This led her to regain self-confident to survive. Currently she has been taking medications as nevilast-30 (Lamivudine, Stavudine, & Nevirapine) and cotrimoxazole, both twice a day. Up to the time of the interview, she had been on ARV for about two months. All of adult members of her family who live in her sister house knew about her HIV status. Her last CD4-cells count was 67/mm^3. She was also friendly and enthusiastically answering the questions during the interview session.

K3

K3 is a 31 years old female, who completed senior high school, and is a widow with three children. She is a Sundanese and claims to be a Muslim, even though she said that she is not a good follower of Islam. Her first child is a 12 years old girl and the second is a 10 years old boy. Both children are from her first husband, who divorced her. K3 has a third child, who is 3 years old, to her second husband who died from complications related to AIDS. She knew that her second husband was a drug user and disclosed, she also used illicit drugs sometimes. K3 stated her second husband continued to use illicit drugs after being diagnosed with AIDS and also consumed alcohol. In 2003, her husband was arrested by the police and imprisoned for about one year. K3 explained that on one occasion she was sharing drugs with her husband. She lapsed into unconsciousness. Her sister took her to a hospital and she was hospitalized for a few days and tested for HIV. The test results showed she was HIV positive.

Following her diagnosis and the incarceration of her husband she ceased using drugs. Her husband was released from prison in 2004. He decided to stop using drugs, unfortunately his health deteriorated rapidly and he was admitted to hospital where he died approximately six months after his release from jail. The doctor in the hospital informed her that her husband had AIDS. K3 was then pregnant with her third child. Although she knew that she was positive, she was unable to refuse her husband’s insistence to have his child. She delivered her baby through spontaneously vaginal delivery and did not receive ARV therapy. When this daughter reached the age of 2.5

years, she was retested with her daughter for HIV at a local NGO clinic. Both were then HIV positive. However, her CD4-cells count was 700/mm^3, which was considered high and did not necessary taking ART. She was concerned for her youngest daughter welfare and is determined to survive in order to raise her children.

When the interview was conducted, she looked healthy and displayed no physical symptoms indicating her HIV infected. However, she frequently complained of headaches when she was tired or when getting emotionally distressed. K3 has known her HIV status for approximately 5 years. Currently she lives in her mother house with her mother, her children, and her sister who is also widow with a daughter. K3's sister works in a private company. Her salary supports the whole family financially. K3 contributes to the family income by selling household gas bottles in her house through cooperation with a gas company.

K4

K4 is a 22 years old female. She completed senior high school and is married to a man who is a drug user. K4 married in 2004 and has a 4 year old son. Before she married, she did not think that her husband was HIV positive, though she knew that her husband was a drug user. She married him after she realized that she was pregnant. Following the birth of their son she noticed she was experiencing vaginal discharge, developed skin lesions, suffered from a chronic cough, and ongoing ears infections. She went to a doctor and the doctor suggested she have a HIV test. She was tested for HIV at a local NGO clinic that returned a positive reading. It shocked her as well as her mother. She was informed by the NGO staff that HIV could be transmitted through needle sharing which commonly happened among IDUs and sexual relationships. She believed that she was infected by her husband. K4's health deteriorated. Her mother took her to the community health center (CHC) where she received TB drugs. She took the TB treatment for a week but was unable to cope with the side effect of the drugs and stopped taking the drugs. Her health status was deteriorating. She lapsed into unconsciousness and was admitted to hospital for several days. During this hospitalization, she received TB drugs for a second time and continued to take them after discharge from hospital for six months as recommended. Her husband was recruited to work for an NGO and was tested for HIV. He was also HIV positive. He was offered the standard ARV treatment, but refused as he felt he was healthy. He believed that ARV was of little benefit in the treatment of this virus and could cause drug resistance. He believed that the doctor prescribed ARV therapy as a universal intervention and did not test for specific virus resistance.

K4's mother said that K4 loved her husband and was highly dependent on him. Before she became very ill with TB, she and her husband lived in her mother in law's house. However, since her mother-in-law and husband's family knew that she had TB, she noticed some unpleasant attitudes from them and therefore she decided to move back to her mother's home. Her mother knew her HIV status as the staff from the NGO staff visited her daughter in her home. K4 has known her HIV status for more than three years. When the interview was conducted, K4 looked unhealthy, showed white layers on her tongue *(candidyasis)*, her weight decreased because she was unable to eat well. There were black spots appeared on her skin and face. Currently she is taking TB medications for the last month of the six-month course, and would continue taking antiretroviral therapy. Although she looked unhealthy, she showed a great attention during the interview and a willingness to share her experience.

From day-to-day K4's health condition was up and down. During the period of my fieldwork, she was admitted to hospital twice and hospitalized for two weeks. One week after the latest hospital admission, her health condition became worse. Her last CD4-cells count was 118/mm^3. Her mother did not take her back to the hospital as they did not believe she would live much longer. Her mother said that K4 had no motivation to recover and gained spirit for life since her husband neglected her and left her. She often closed her mouth and did not talk and nor eat anything. Then, on one day, she got severe diarrhea with dark secretions in her feces. It was her last activity, and finally she released the last breath and died.

K5

K5 is a single man, 27 years old and a former IDU. He completed senior high school, is living with his parent, and two younger sisters. He has been a drug user under influence of his friends since he was at senior high school. His mother had ever caught him when he and his friends were injecting drugs near his home. He has used drugs for about three years. Several months after he graduated from high school (2004), he began to develop signs and symptoms such as cough, diarrhea, and decreasing body weight. The family took him to a nearby hospital, but that hospital refused him without showing an acceptable reason. Later, he wanted to go to a private hospital but the family finally brought him to the provincial public hospital. He was admitted for about eleven days. There, he received TB drugs and took those after being discharged until the nine-month treatment course was completed. At that moment, he also got an HIV test and he heard that he was infected. Since then, he decided to quit from the drugs though he could not quit from taking alcohol and smoking. On April 2005, he started to receive anti-retroviral therapy from a public hospital. Under influence of his friends, he moved from the public hospital to a private hospital to get anti-retroviral therapy. Unfortunately, the stock of ARV in the private hospital was sometimes limited. That forced him to come more often to the hospital to take the ARV medications. Ultimately, he was too lazy to visit the hospital and stopped taking ARV medication due to the inconvenient service of the hospital. An official of an NGO approached him to get back to hospital for continuing taking ARV medications.

When the interview was conducted, he looked quite healthy though his posture looked thin. He had known his HIV status for more than three years. His last CD4-cells count result was 415/mm^3. He was still cheerful, friendly, and humorous, even with a stranger. He spoke fluently and he was able to response the questions appropriately. Currently he did not have a permanent job. However, in order to get income, he attempted to sell food near a road intersection close to his home.

K6

K6, a 36 years old male, completed high school, and used to work as a public motorcycle driver. He is married and lived with his wife (27 years old) in a rented room in a sub-urban area next to Bandung City. K6 is the fifth of seven children in the family. His father had passed away in 1985, followed by his mother in 1990. After loosing his parents, he stayed with his brother for a temporarily until he got married in 2005, and then lived with his wife in a rented 4x3 m^2 room. K6 used to be an IDU since 1998, thus for nine years. At the beginning, he often shared needles with his peers, or he used contaminated needles from his friend. By mediation of an NGO, he got around mid-2007 an HIV test and the result was positive. At the time he was not clearly aware about HIV, and thus just ignored it. However he tried to reduce the frequency of using drug as well as the dose. One day, he observed his friend died because of AIDS, and saw the people being scared and avoiding coming close to the death. That led him to believe that HIV and AIDS were possibly true. Shortly after that, he developed symptoms such as weakness, feelings unwell, and enlargement of the lymph nodes in his neck. Some enlarged nodes erupted with some discharge. His brother took him to a medical doctor specialist in a private clinic where he was diagnosed of having lymph node TB and received TB medication for 6 months. These drugs included rifampicin, INH, and pyrazinamide that must be taken once a day for each, and he also got ARV treatment with nevirapine, stavudine, lamivudine which need to be taken twice a day for each, and cotromoxazol for once a day.

When the interview was conducted, K6 was in the stage of recovery from his illness. His posture looked thin, he complained about fatigue, and his foot palm was numb and painful when touching the ground without sandals. The two dressed gauzes covering wounds on his neck, looked clean when exposed and showed no discharge. Up to the time of interview, he was still taking the prescribed medicines under supervision and caring of his wife. His last CD4-cells count was 173/mm^3. He looked friendly and able to communicate very well.

K7

K7, a housewife, aged 18-year, graduated from primary school, living with her mother in a ± 6x5 m^2 rented room. She got married with Mr. H. (24 years old) in 2005 and currently have one son, A., 3 years old. K7 knows her HIV-positive status since June 2008. At the time, her son was sick with symptoms of fever, cough, and persistent diarrhea for more than one month. Her son’s body weight has drastically decreased, just skin-over-bone, and he was then very thin, and he was admitted to hospital for about two weeks. The doctor who cared for her son suggested her son needed to get an HIV test. After knowing the son was HIV positive, the doctor also suggested K7 and her husband to get HIV test. She was very shocked after hearing that she, her husband, and her son were all three HIV positive. K7 and her mother thought that her husband had HIV and had infected her. At that time, her CD4-cells count was 86/mm^3, yet no physical symptom showed up. After her son was discharged from hospital, she decided to live separately with her husband. She chose to live with her mother and her husband lived with his parent, whereas A, her son, sometime stayed with her, sometime with his father. She has received ARV therapy with Neviral and Duviral twice a day. However, she stopped taking ARV after two months of medication, due to financial constrains to pay transport and registration fees. She was boring by the long queue and lengthy time to get ARV in the hospital and at the same time she also had to take her son to get TB medicine and ARV. She felt too exhausted to follow up and getting medication in hospital, therefore she was reluctant to visit the clinic for continuing taking ARV medication.

When the first interview was conducted, she reported feeling fatigue, having diarrhea for about three months, losing weight from 50 kg to 42 kg, and occasionally having nausea and vomiting. Nevertheless, she was still able to carry out mild daily activities and communicate well. So far, her mother, Mrs. M, 41 years old, a widow, who primarily cared for K7 and her son. A week later, K7 was admitted to hospital when her condition became worse, caused by diarrhea. I had a chance to visit her while she was in hospitalization until has observed that she was getting better and could discharge from hospital.

K8

K8 is a housewife, 32 years old with a bachelor degree. She has married with Mr. X (32 years old) six year ago. Mr. X used to be her classmates while she was at the university. Right now, she has two children, the first child is a boy, 4 years old, and the second is daughter of 1 year. K8 has known her HIV status since 2006. At that time, her husband was admitted to hospital with symptoms of chronic cough, fever, and losing body-weight. The doctor noticed Mr. X's tattoo and his history as a drug user. Therefore, the doctor suggested to get an HIV test, and the result was positive with CD4-cells count of 30/mm^3. K8 was tested too and proved positive with a CD4-cells count of 600/mm^3. Fortunately, her son was negative, and her daughter had not got a test at the time of interview. She was first very depressed of knowing her HIV-positive status, although she suspected before getting married that Mr. X was a drug user. Mr. X seemed to have convinced her that he had stopped from taking drugs, so that is why she accepted to marry him.

She felt deep regret after knowing she had been infected by her husband, she decided to leave him and stay with her parents for about 6 months. During that stay with her parent, she did not inform them about her status, she just told her parent that she had problems with her husband and needed to live separately, however she worried that if her family would know the truth she would get an improper treatments from her parents. After six months, her husband asked her and persuaded her to live with him again. She accepted her husband's offer and she moving to live with her husband's family. Her husband's family knew their HIV status and they showed strong supports and courage for her. Unintentionally, she got pregnant of the second child. At the seventh month of her pregnancy, she had developed symptoms such as fatigue, nausea, vomiting, and diarrhea for about one month. She was admitted to hospital and had a CD4-cells count test with resulted in a score of 150/mm^3. She received ARV treatment with duviral and efavirenz twice a day and continued up to the present time. The doctor suggested her to have a caesarean section for her delivery, and her baby had to take ARV for two weeks. Her family, ultimately, knew her HIV status, because of their curiosity to know what had happened to her and why she had to be treated specially. Fortunately, her parents understood everything and had no problem with her condition, therefore her parents welcomed her if she and her husband wished to live with them. Nevertheless, her relatives such as her aunt had tried to persuade her to divorce from her husband to avoid being further infected by him. Presently, she and her husband as well as their two children live in a rented house near her parents' house. When the interview was conducted, K8 looked healthy, was able to fluently communicate with the researcher, and to carry out daily activity as normal people. She was pleasant to share her experience with the researcher.

K9

K9 is a 23 years old male, married, graduated from junior high school, and works as a motorcycle for rent driver. He married his wife when he was 19 years old and his wife was 14 years old, as she was then 2 months pregnant. K9 has known his HIV positive status since June 2008 while his son was admitted to hospital and diagnosed of being HIV positive. At that time he also got an HIV test and the result proved positive with a CD4-cells count of 85/mm^3. He was shocked and regretful that he had ever engaged with a prostitute. He received ARV with Duviral and Neviral twice a day, however he was just able to take ARV for two months, later, he dropped out due to financial constrains. Moreover, his mother who used to take him to clinic, started then another business and was unable to escort him regularly to clinic. After stopping with taking ARV, he began to develop coughing, fever, fatigue, and loosing body weight up to 10 kg. His mother took him then to a hospital where he admitted and diagnosed of having lung TB. After 9 days hospitalization, he was getting better and his body weight increase gradually. He started to take TB medication for an eight-months course, however, again, he was just able to take TB medication for five months and stopped for 1.5 months due to financial problems and his 'wrong' idea that he had recovered already. One month after he stopped medication, he developed coughing again and fatigue. Then, his mother took him to a clinic and he continued with TB medication for the second time. While he felt his body was getting better, he often worked until late night and he also did smoke as well as drink alcoholic beverages. His condition became weak again with symptoms such as coughing, fatigue, nausea, stomach discomfort, anorexia, and reduced body-weight.

Most of the time he was cared at home by his mother. He did not want to be taken to a hospital. He was depressed and had told his mother that he did not want to live longer. Since he was diagnosed HIV-positive, his wife with his son had left him. In his family, he was the third child of eight children. His oldest brother was a Down syndrome survivor, his father had got a stroke five years earlier. His father did dislike him, even cursed him, since he was caught while having premarital sex with a girl in his house. His father was religiously obedient and often blamed him with such misconduct behavior as non compliance to medications, drinking alcohol, having sex outside-marriage, or sleeping too much. This situation caused stress and discomfort when living in his father's house. He felt comfortable when his mother was present. She fully understood his problems and cared for him.

When the interview was conducted, he was sick and cared for at home by his mother. He developed dyspnea, cough, stomach pain, and lack of appetite, however he was first still able to communicate and walking a short distance. One week after the interview, his condition became worse, he was unable to eat and drink, and he was admitted to hospital. Unfortunately, it was too late and after 4 days in hospital, he died.

K10

K10 is a 27 years old male, a former IDU, is married, has a seven years son who is currently sitting in first year o the primary school. Previously, K10 used to work for a private company, yet since he often feels fatigue, he quitted from his job and started to run a small shop near his parent's house. Presently, he is living in his parents' house with his parents and his younger brother. K10 had been a drug user since he was in senior high school and continued until his third year in a college. At that time, he often shared needle with his friends while injecting drugs, due to non available sterile needles and ignorance about the risk of infection. After using drugs for about ten years, he began in 2007 to develop typical symptoms such as headache, losing weight, fatigue and lack of appetite. His weight dropped and he was looked very thin and sick. He was taken to a private hospital and hospitalized for two weeks. In the hospital he was HIV tested and the result was positive. At that time, he ignored it and did not care about HIV. After getting a bit better, he was allowed to go back home. A few weeks later, while he felt better and healthy, he started to inject drugs again with his friends. Shortly after that, he began to develop respiratory problems such as coughing and his weight decreased again. He was admitted for two weeks in a lung hospital and received TB medications. His weight gradually increased after several months taking TB medications. Again, he felt much better and he was tempted to inject drugs. One day, he noticed his health condition became again rather poor. He developed severe headache, coughing, and a little blood came out through his nose and ears. He fell while in the bathroom and was unconscious for a while. He was admitted to a private hospital and underwent hospitalization for two weeks. He was checked for CD4-cells count and the result was $2/mm^3$.

An HIV-counselor of an NGO approached him and motivated him to take ARV medications. Previously, he had never thought to take ARV due to fear of side effects and burden for taking ARV medications life-long. However, after considering the suggestions of the counselor as well as the health-care providers in the hospital, he finally accepted to take ARV medications. His last CD4-cells result was $500/mm^3$.

When the interviews were conducted, he looked healthy, though a bit underweighted. He stated that he had stopped using drugs since the last discharged from hospital. However, one thing that made him most concern was his wife. Since the first time she knew K10’s HIV status, she was also positive, and she had left K10 and lived with her parents. Their son most of the time followed his wife. He has tried to reconcile and ask her wife to live together, yet she refused and seemed to have an affair with another guy. During interaction with the researcher, he showed good attentions and willing to share his experiences.

K11

K11 is a housewife, 39 years old, who completed senior high school, and has a 5 years old son, who currently goes to kinder-garden. She married for the second husband at the end of 2008, after being widowed for about 4 years. The first husband, who is suspected to have infected her by HIV, had passed away four year ago. He was a Malaysian, worked as an architect, and married with her while she was a worker in Malaysia in 2001. In 2002/2003, she got pregnant and went to Medan, Indonesia, for delivering her baby. She preferred to deliver her baby in Indonesia in order to easily get Indonesian citizenship for her son. After delivering the baby, she and her husband returned back to Malaysia. However, her husband began to develop an illness that caused him to be admitted to hospital. Her husband was unable to work again, and she also had stopped work since she married, because her company did not allow a worker to marry. She decided to go back to Indonesia and was followed by her husband. After about two months living in her hometown, her husband's health condition became worse. He developed severe diarrhea, cough, and losing body weight. She took her husband to a Lung Clinic in Bandung, where he was advised to get treatment in hospital, yet he refused to go to hospital. Ultimately, in 2004, he died at home without knowing the specific disease which caused his death. Six month later, K11 went back to Malaysia for finding a job, however she had to get an HIV test as a requirement. She was surprised that the result was positive. The company who would employ her refused to accept her as a worker, and sent her back to her hometown with an official statement about HIV test result.

She was very upset with her late husband who had infected her with HIV. However, it had happened already and it was impossible returning back to previous time. She just submitted this problem to God, and tried to contact the Community Health Center to confirm her HIV result and take necessary steps for treatment. She was recommended to visit an NGO and by assistance of an NGO she was able to confirm the result with the second HIV test, which showed a CD4-cells count of 200/mm^3. She was receiving the ARV treatment from a private hospital in Bandung.

During the period of ARV treatment, she had missed the pills for a week due to being busy with her work as a vegetable seller in a market. It resulted in a drop of her condition and she developed symptoms such as fever, diarrhea, and decreasing body weight. She was admitted in a hospital for a week and continued to have ARV treatment. On June 2008, she took CD4-cells test with a score of 280/mm^3. Since a month ago, she has tried to complement ARV treatment with urine therapy that was recommended by her counselor. The result was quite satisfying since she noticed that her body weight was gradually increasing. When the interviewed was conducted, she looked healthy, was cheerful, and friendly. She was able to express her feelings and share her experience fluently.

K12

K12 is a 33 years old male, is married, is an IDU, and works for an NGO. He has been an IDU since 1996. Presently, he is still using drugs though the frequency has been decreased. He knew about his HIV positive status since 2006 after he underwent an HIV test by facilitation of an NGO. His CD4-cells level was 24/mm^3 at that time. He intended to check HIV because he observed some of his friends who often injected drugs together and shared needles with him had developed serious illnesses that led them to die. At that time he felt scared and wanted to know his status. After knowing his status, he was shocked and down; he often kept himself in his room. Fortunately, an NGO helped him to get support particularly from his family and his wife. He has been taking ARV medications with neviral and duviral twice a day since knowing his HIV status. Since that time, he tried to reduce the frequency as well as the dose of injecting drugs. However, he was still unable to totally quit from the drug due to its addiction. He tried to reduce the risky behavior by using sterile needles provided by NGO. He had once changed from injecting drugs to oral methadone substitution, but it did not work successfully and even resulted in severe craving when he missed the methadone for a day. Finally he stopped methadone and backed to inject drug with different substances than the previous ones. At February 2008, he checked his CD4-cells level and the result was 577/mm^3.

When the interviews were conducted, he often complained having unwell feelings such as fatigue, lack of appetite, and a bitter taste on his tongue. He was a heavily smoker, taking more than one pack of cigarette per day. Presently, he lives with his wife who has married him three years ago. His wife was very helpful and keen to care for him. His wife has got a test two years ago, and her result was positive with a CD4-cells count over 700/mm^3.

Table 1

Demographic Characteristic of Key Informants (n = 12)

Variables	Number
Gender	
Male	6
Female	6
Marital status	
Married	9
Single	1
Widowed	2
Age (years)	
20 - 30	4
31 – 40	8

Table 1 *(Continued)*

Variables	Number
Educational level	
Elementary	1
Junior high school	2
Senior high school	8
Bachelor Degree	1
Employment	
Unemployed	1
Self-employed	5
House wife	6
Income (IDR/month; 1 USD = 9,300 IDR)	
No income	4
< 1,000,000	7
1,001,000 - 2,000,000	1
> 2,000,000	0
On ARV medication	
Yes	7
No	5
History of Injecting Drug User	
Yes	6
No	6
Length of time since diagnosis HIV	
> 6 months – 1 year	2
> 1 year – 5 years	10

In brief, the key informants consisted of six males and six females. Their ages were 18 to 39 years with the 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 (lower than the district's official minimum income) to meet daily needs. Six of them were former IDU, whereas six others were wives infected by husbands. Ten of them have been on ARV medication, but three dropped out. Ten of them have been living with HIV for more than one year since knowing their HIV diagnosis. The summary of characteristics of the key informants is attached in the Appendix J.

Characteristics of general informants

The general informants consisted of eight primary family caregivers, nine health care providers, and nine community leaders. Community leader refers to the ones who have strong influence in the community through their knowledge and experiences regarding community matters. They included formal leader such as village head man, sub-village leader, neighborhood leader, religious leader, youth leader, NGO staff, the District AIDS Commission staff, and community health volunteer. Family care givers were interviewed, whereas health care providers and community leaders were engaged in focus group discussion separately. In this study, the general informants were referred to by a pseudonym from G1 to G26. General informants consisted of nine males and seventeen females. Their ages were ranging from 24 to 70 years old with the mean age being 43.12 (SD= 12.972). The characteristics of the general informants are presented in the table 2.

Table 2

Demographic Characteristic of General Informants (n = 26)

Variables	Family Care Givers (n=8)	Health Care Providers (n=9)	Community Leaders (n=9)
Gender			
Male	1	2	6
Female	7	7	3
Marital status			
Married	4	6	9
Widowed	4	-	-
Single	-	3	-
Age (years)			
20 - 30	1	2	1
31 - 40	-	3	2
41 - 50	3	3	3
> 50	4	1	3
Educational level			
Elementary	1	-	-
Junior high school	4	-	2
Senior high school	3	-	4
Diploma III	-	5	-
University	-	4	3

Table 2 *(Continued)*

Variables	Family Care Givers (n=8)	Health Care Providers (n=9)	Community Leaders (n=9)
Employment			
Farmer	1	-	-
Government employee	-	-	1
Private	1	-	5
House wife	6	-	3
Nurse	-	6	-
Physician	-	2	-
HIV Counselor	-	1	-
Relationship with key informants			
Mother	6	-	-
Father	1	-	-
Wife	1	-	-
Duration of caring for PLWHA (years)			
0 – 1	2	2	-
> 1 – 5	10	6	-
> 5 – 10	-	1	-

Perceptions about HIV and AIDS, and Living with HIV infection

> *"The sky looks like… it is going to collapse. I look to the future; it is dark. I feel the angel is going to draw my soul in a few seconds. I am really hopeless and have no spirit to continue my life." (Pikiran Rakyat, 29-05-09)*

The above statement was cited from a daily local newspaper published to reflect how a newly HIV-diagnosed person expressed his feelings when knowing his HIV status. This statement was articulated as a synthesis of patients' perceptions and knowledge about HIV, and their perceived living with HIV infection along with the various related impacts that are a consequence of being an HIV-infected person. The following section presents the findings of this study which are divided into two major categories, namely perceptions about HIV and AIDS, and perceptions about living with HIV infection. These are described as follows:

1. Perception about HIV and AIDS

The terms HIV and AIDS were perceived in various ways among our key and general informants. Informants exposed to NGOs and/or health care providers perceived HIV/AIDS as an illness, which closely resembles the definition according the medical perspective. For example, six key informants and three family caregiver informants were able to distinguish between the terms "HIV" and "AIDS" correctly. They said that the term "HIV" referred to the virus, whereas "AIDS" referred to the severe condition of the HIV-infected person. However, before learning from either NGOs or health care providers, the informants perceived HIV as having a similar meaning with AIDS. Some words used by the informants to closely represent the meaning of HIV/AIDS were *"penyakit wanita nakal"* (illness of a prostitute, or of a woman who engages in sexual relationships with multiple partners outside the marriage), or *"penyakit pria hidung belang"* (illness of a womanizer). The dominant media coverage in the early stage of the HIV epidemic, which associated AIDS with sex workers or prostitutes, had driven public opinion about HIV and AIDS toward the idea that they were closely linked with promiscuity. In addition, all of the community leader informants expressed an unclear understanding of the exact meaning of HIV and AIDS, including their characteristics. Two informants asserted that AIDS could be a more severe disease than HIV, and that an HIV-infected person might even look healthier than an AIDS person. In this context, the term "HIV illness or HIV infection" were used instead of AIDS since it represented the informants' assumption that the HIV illness might have a wide range of conditions, from relatively healthy to very poor conditions (AIDS). Among the informants, common perceptions regarding the HIV illness, which represented their understanding about the illness, were shared. Four themes related to perception of HIV and AIDS emerged. These were: (1) HIV as a deadly illness, (2) HIV as a dirty illness, (3) HIV as a horrifying illness, and (4) HIV as a young people's illness. These perceptions are described as follows:

1.1 HIV is a deadly illness

Perception of HIV as a deadly illness was initially expressed by all informants in this study. Six key informants perceived HIV was a deadly illness due to the fact that this illness causes death. The other six key informants perceived that HIV was a deadly illness; however, they maintained that it could be managed by following medical prescriptions. The image of HIV 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 key 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)*

Similar terms with "deadly" illness such as "severe illness", "killer illness", "fatal illness", and "incurable illness" were also shared by family caregivers and community informants. The term "incurable illness" was mostly perceived because of the unavailability of medicine to cure the illness. As one family caregiver expressed:

> *"It is miserable! Why did this happen to my daughter? It is really a severe illness, an incurable illness, because, right now, there are no medicines to cure it and many people have died because of this illness." (G4)*

One community informant also stressed that HIV is a fatal and a killer illness, when he said:

> *"I think HIV is a very fatal and a killer illness that can cause death in a short period of time because of the unavailability of a cure for it." (G21)*

1.2 HIV as a dirty illness

Six key informants, who were wives infected by their husbands, and five family caregiver informants initially viewed HIV 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 our 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, as a family caregiver expressed:

> *"I was wondering when my daughter began to complain of having pus discharges with bad smell from her genital organ. I thought it might be what common people called "raja singa" which is known as a dirty and disguising illness because of its symptoms. It was hard to believe it because she is not a prostitute…the doctor suspected her to be infected by HIV and advised her husband to get tested. That is why I think HIV is a dirty illness." (G2)*

The key 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 key 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)*

Family caregiver informants maintained that HIV or AIDS was a dirty illness because of media stereotyping of HIV as a prostitute-related illness. One of them said:

> *"…what I know so far from mass media, is that HIV is a dirty illness, linked to promiscuity and associated with people such as prostitute women and "pria hidung belang" or men who frequent prostitutes…" (*G3)

When exposed to the more updated information about HIV and AIDS, the perception of our subjects was redefined. They learned that, although it was still incurable, HIV-related symptoms could be managed and life expectancy of PLWH could be improved by taking good care of one's health and taking antiretroviral drugs. This is supported by the statement of one key informant, as he said:

> *"… Since I learnt more from the NGO staff and health care providers, I now know that HIV is not something dirty, because many of its symptoms can be managed by taking good care of one's health and receiving ARVs. It could also affect innocent people such unsuspecting wives or children, so it doesn't mean they are immoral. As for me, I also got infected through sharing a contaminated needle, and I had never known about this route of transmission before." (K6)*

1.3 HIV 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 key 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 can not 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)*

Although our key informants were presently able to face HIV infection without feelings of fear, they still believed that the majority of the general public, who were unexposed to valid information related to HIV and AIDS, would remain fearful of this illness. One key informant shared her experience when observing people in her community scared to be in contact with someone who had died because of AIDS, though their help was needed to care for the dead body. She said:

> *"I noticed that people here were so fearful to this illness when one of our neighbors died a couple of years ago. The NGO staff took the initiative to collect donations from the community to support the man who was suspected of suffering from AIDS to get hospital care. Unfortunately, he died and when the dead body got back home, the surrounding people ran away and no one braved him/herself to get close and help care for the dead body…" (K9)*

The HIV as a horrifying illness was also confirmed by all of the family caregiver informants in this study. Family caregivers agreed that this illness had created fear in most of the general public. A mother narrated her feelings sadness when knowing her relatives and neighbors had run away from her dead son's body when she said:

> *"What I feel is that AIDS is a really scary illness. An infected person can die quickly as a result of it, due to no available medicines to cure it. This makes many people scared of this illness. I am wondering why it happened to my son? It was very sad when I noticed that nobody here was willing to care for my son's dead body when it arrived home from hospital…" (G6)*

The feeling of fear was also experienced by all family caregivers in the beginning stages of knowing HIV status of their family member. However, they tried to overcome this feeling by considering caring for the sick family member as a cultural and religious obligation. In addition, blood ties and the emotional bonding between parent and child, or the love between wife and husband, instilled a strong power to put the feelings of fear aside and, instead, to commit to caring for the sick family member. However, they remained precautious when taking care for the HIV family member. A father who was a family caregiver for an AIDS family member explained that he had taken strict precaution to prevent further transmission to other family members by disposing of, or burning all contaminated linen, clothes, and other used items by the patient. Another caregiver also expressed feeling scared when caring for the first time for an open wound of her HIV positive son, as follows:

> *"The first time I did wound dressing for my son, I felt scared because I knew from hospital staff that this illness could be transmitted through wound discharge as well. Yet, I tried to handle this feeling by taking precaution through hand washing using soap before and after wound dressing." (G1)*

Similarly, the feelings of being scared of this illness were also reflected by all health care provider informants who attended group discussions. They recalled this feeling initially came up at the first time they were assigned to care for the HIV patient. However, as time passed and some of them became exposed to professional training related to HIV and AIDS, they were able to cope with this feeling. Seven health provider informants were involved in several kinds of training related to HIV and AIDS such as VCT counselors, adherence counseling, and IMAI (Integrated management of adult infectious diseases). Meanwhile, three of them had no prior special training related to HIV and AIDS. All health care provider informants perceived their job as risky to contracting HIV, particularly when personal protective measures were improperly applied due to lack of resources. While visiting a key informant admitted in a hospital ward, I observed that nurses were rarely physically present beside the "B20" (substitute code for HIV/AIDS patient) patient when the patient needed their assistance; most of the basic care for the patient was carried out by family caregivers. At that particular time, another B20 patient was very ill and had severe diarrhea and lung TB; however, there was no bed available of a private or isolated room for such patient in the ward. Three health care provider informants who work at the nursing wards expressed their concern about caring for AIDS patients when personnel protective equipment were lacking. One of them said:

> *"Yeah, particularly for us who work in the nursing ward, we are rarely exposed to up-to-date knowledge and skills about caring for HIV/AIDS patients. So, some colleagues still think it is a scary illness. They are scared of its transmission, particularly when self-protection equipment is not sufficient." (G16)*

Likewise, all community informants also expressed the same feeling related to the HIV. They narrated that many members of the general public were really fearful of this illness due to the nature of the illness which is easily transmittable and can cause death. In addition, they said that many lay people lacked valid knowledge about HIV and AIDS. People generally get their information about HIV and AIDS from public media which sometime does not present detailed information about this illness. In addition, the media coverage related to the topic of HIV and AIDS frequently contains scary words or sentences in the headlines. For example, the words that are commonly used in the newspaper such as "Your rhetoric leads to my death", "The number of AIDS patients is increasing", "... (number) of people with AIDS died", "… (number) new HIV cases were found", "… (number) of children under five years of age have HIV/AIDS", etc. These provocative words might contribute to the image of HIV as a fearful illness. A housewife who is a health volunteer in the community expressed her feelings as the following:

> *"As a housewife, I am afraid when I hear about HIV, because I have children and my husband lives far away. I don't know what he does, because nowadays everybody seems to be vulnerable to contracting HIV. If someone in a village has HIV, it could easily be transmitted to other people. HIV is a killer illness with no known cure, so we have to prevent it." (G18)*

On the other hand, due to the misperceptions about HIV and AIDS among community people, six community informants thought that HIV could be transmitted through physical contact, saliva, sputum, used linen, and sharing a drinking cup with the infected person. As one community informant stated in the following statement:

> *"Even though I am not fully informed about HIV and AIDS, I believe it is very fearful. When I read the newspapers, I see that this illness is spreading over time. I think it is not only transmitted through sexual contact but also though physical contact, touching, saliva, sputum, even sharing a drinking cup or utensils with the infected person. Indeed, it is like a horror-struck illness." (G19)*

1.4 HIV as a young people's illness

This perception was mainly observed among seven community leader informants who were concerned about the future of future generations. This understanding was generally derived from media coverage of HIV/AIDS which indicates that young people constitute a high proportion among people infected by HIV, particularly those who have a background of IDU. This was relevant with the fact that in this town, 56% of people infected with HIV were also IDU. As one community informant put it:

> *"HIV is young people's illness. I have noticed some newspapers mentioning that, in our town, the method of HIV transmission is mostly via contaminated needles, and most IDUs are young people. This is possible especially since the narcotics problem has been uncontrollable in the last decade. Therefore, if we want to tackle HIV, we must first tackle narcotics." (G22)*

This notion was confirmed by the key informants who agreed that most HIV infected persons were IDUs, the majority of whom were young people. Key informants with an IDU background perceived being an IDU when they were young as a form of teenage naughtiness as a result of curiosity toward new experiences of self-actualization, or peer pressure to be accepted by peers. Previously, most of them did not know that their behavior of sharing contaminated needles was a risk to contract HIV. This notion was also confirmed by my observation through available documents related to HIV such as official reports, slide/video presentations, newspaper excerpts; as well as meetings and interaction with people living with HIV/AIDS, NGO personnel and HIV activists who supported the claim that young people were the most vulnerable to contract this illness. One key informant expressed his concern about HIV as young people's illness by saying:

> *"It could be said that HIV is a young people's illness since a large proportion of young adults are infected. Like me, who started using drugs when I was 15 years old, in the 2nd grade of Junior High School, in 1992. I continued until 2003, and then I started injecting in 2003 and continued until 2007, when I was diagnosed with HIV and stopped to using drugs. Yeah, my friends and I were still young at the time; at just 27 years old, I am still young and not married yet." (K5)*

2. Perception about living with HIV infection

Being an HIV-infected person generated a deep insight among key 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. One key informant, a 27-years-old man, who used to be an IDU and quit after being diagnosed with HIV and who had experienced severe impacts from the illness, eloquently narrated a piece of his life story to reflect his living with HIV as follows:

"I was a drug user for about ten years, since when I was in high school. My life was a mess and fueled by illusions. Everyday, I only thought about how to get drugs. We rarely exposed ourselves in public, because, if people knew, they would blame us and report us to the police. My belongings given to me by my parents were

sold out to make money for drugs. I cheated my parent by spending my school fee on drugs till I dropped out by the third year of college. At some point, I developed physical symptoms such as fatigue, lack of appetite, diarrhea, and weight loss. My mother took me to hospital and got me admitted for two weeks. I got an HIV test at the time, and the result was positive. I denied the truth of the result because I thought it was impossible for this to happen to me. I hadn't engaged in sex with any prostitute or had any sexual intercourse, though I was naughty at the time. What I knew was that HIV was only a prostitute's illness. I was discharged from the hospital and I continued to inject drugs. During the following months, my health condition deteriorated again and I suffered symptoms of coughing, breathing difficulties, and decreasing body weight due to a lack of appetite. I was sent to the Lung Hospital where I was diagnosed with tuberculosis and received TB treatment for 6 months. Again, after my health got better and my weight started increasing, I was tempted to inject drugs again; this went on for a couple of months. Finally, I thought that this was a punishment from God. I later experienced severe headaches; it seemed like my head was being stricken repeatedly by a big hammer. One day, I fell down unconscious when I was in the bathroom. I have no recollection of what happened afterward. My mother said that I was bleeding from my nose and ears which led me to be readmitted in the hospital. An NGO staff and a senior nurse approached me and persuaded me to take ARVs. I was really impressed with these two guys who sincerely and genuinely cared for me. Previously, I had refused to take ARVs, yet, at this time, my mind was opened and I agreed to take ARVs. I am grateful to those two guys. Unfortunately, my suffering has not ended yet. My dear wife left me. She took our son and now lives with her parents. She said she regretted having even been with me who had brought this illness to her. Actually I have apologized to her and asked for reconciliation, yet, she was very hurt by this situation, and, currently, I heard she has another guy. This is really hurtful.

Luckily, my mother always supports me. She has sacrificed everything to help me recover from this terrible illness. I used to work for a private company, but, because I often felt tired, I missed work often. My boss investigated me, and when he learned that I was HIV positive, he asked me to resign from the job. I strove hard and learned to cope with these difficulties. This is a great test from God for my life. Although I am not a strongly religious person, I still have "iman" (faith) in God's power and authority in my life. I have to be "sabar" (patient) in dealing with these difficulties. So, I think my "iman" and "sabar" are being tested by God to prove whether I am able to turn back to the right way and consistently behave in the right way. If I had failed to recognize this warning, I might have still continued using drugs until my death, or otherwise continued to have the feelings of guilt, frustration, and despair, which might have led me to commit suicide. Obviously, the NGO staff and the nurse were greatly helpful and an encouragement in guiding me to gain my self-confidence. Nowadays, I am striving to enjoy the remainder of my life. I have a son, he is still young, seven years old, and now lives with me and my family. It is my responsibility to raise him up until he becomes independent. I am also continuing to persuade my wife to come back to me. I advised her not to marry that other man because it would spread the infection, which is considered a sin. I told her that I promised to "insyaf"(repent), i.e., trying to completely leave my bad behaviors and starting a new page in my life by doing more good actions, e.g., fulfilling my

> *responsibility to my family. You see now, I have been starting to run this food stall, and, thank God, I am able to earn enough money to support my daily life and my son, though it is not much. I know that I am living with an illness that makes most people feel fear, but I don't care too much about it. I still keep contact with people as necessary. However, I still conceal my HIV status because it is not necessary to let people know; people would only laugh and mock me. It is only me, my wife, and my mother who know the truth that I am HIV positive. I think it is fine with me to accept it is as my fate from God. I have to evaluate myself and improve my life and, yes, it should never happen again to the next generations. I have learned that living with HIV is like living under shadows of death. Many of my IDU friends have already died. I thank God for granting me life though I am a sinful person. This time is to return to the right way and submit everything to God, while striving to enjoy the remaining life. Hopefully my future life will get better." (K10)*

The above story illustrates how the perception about HIV and AIDS and the real experience in dealing with the illness trajectory has shaped the construction of the meaning of living with HIV in daily life. The explanations from other key informants and my observations also confirm a particular perception which can be categorized into three themes. These are, (1) being tested of *iman* (faith) and *sabar* (patience) through the ups and downs of HIV-related suffering, (2) time for doing *"mawas diri"* (self-evaluation) and "*insyaf*" (repentance), and (3) shadowed by the feeling of *"malu"* (embarrassment). Each theme is 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 our subjects to accept their condition as a test set by God for their *iman* and *sabar*.

The perception of living with HIV infection as a test of faith and patience was stronger among the informants infected by the husband. Six wives perceived their circumstance as a great test for them as innocent persons, because they had never engaged in any risky behavior before marriage. One key informant illustrated this perception by referring to a local proverb, which goes “someone else eats the jackfruit, yet, another gets the effect of its sticky gum”. It means that they were innocent; they did not bring the HIV infection upon themselves, but they got infected by their husbands. 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 key 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 key 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 significant 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 key 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)

Our 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 key 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 key 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)*

The key informants accepted that using illicit drugs was prohibited by religion and considered a sin. However, the experiences of dealing with severe suffering because of AIDS-related symptoms had taught them to appraise these experiences as a punishment given by God. By this punishment, one was supposed to do *insyaf* (quit one's sinful behavior and go back to the right way). One key informant expressed his experiences of being a relapsed drug user. He had been sent to the rehabilitation shelter over a period until he physically collapsed due to severe AIDS symptoms. As he said:

> *"I have been sent to the narcotics rehabilitation shelter by my family about three times. Ye, every time I was discharged and met my previous friends I relapsed again to injecting drugs. One day, my health condition had deteriorated which brought me to hospital and I knew that I was HIV-positive. Afterwards, many symptoms came over and over and I think this is like a punishment from God because I didn't pay attention to His warnings. That way I "insyaf" by quitting and striving for a better life." (K6)*

Informants recognized that living with HIV infection meant being shadowed by death. Although they knew that death is inevitable for every living thing at some point of time, HIV infection indicated that the end of life became more clearly determined. This was reflected by one informant who claimed that being infected with HIV-infected was like having a ticket already in hand and waiting to be called by God. Fortunately, by continuing to take pills (anti-retroviral drugs) he has gained great benefits and the informants' health was improving and this was delaying death. However, such success had not come easily in the informants' real life. There were so many challenges that resulted from the impact of HIV-related and he had to deal with the side-effects of ARV medication as well. This required sufferers to strive to overcome various HIV-related problems in order to prolong their lives. One key informant said:

> *"I learned living with HIV is like being under the shadows of death. Many of my IDU friends had died already. I thank God that He still granted me life though I am a sinful person. This time is the moment to "insyaf" back to the*

> *right way, and submit everything to God while striving to take benefits from this remaining life. Hopefully my future life is getting better." (K10)*

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

Key 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 infection 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 key 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)*

Meaning of Caring and Self-care Activities of Persons Living with HIV Infection

Informants viewed caring as an integrated part of their life since they learned that their body was infected by HIV which caused them to be vulnerable to health problems. The advancement of anti-retroviral therapy has resulted in improving life expectations among PLWH. However, having a chronic illness such as HIV still imposed burdens of care that need to be carried out by PLWH themselves or with the assistance of others. The key informants shared their visions and experiences in caring for themselves with HIV infection in the context of a Muslim community. Two categories were presented related caring for PLWH: the meaning of caring for persons infected with HIV-infected; and self-care activities by PLWH to maintain their health and well-being.

1. Meaning of caring for persons with HIV infection

Caring in the context of living with HIV infection has been illustrated by key informants as a reality that has to be accepted. They submitted to the reality of having HIV infection to God as the source of ultimate hope and power according their beliefs. Four themes emerged that reflected meanings of caring from key informants' perspectives. These were: (1) accepting the reality of having HIV infection while *"pasrah"* (submitting self) to God; (2) striving to maintain health by performing optimum *"ikhtiar"* (effort) and *"do'a*" (supplication); (3) gaining the blessing of God by doing *"kebaikan"* (good deeds) and worshipping; and (4) building *"persaudaraan"* (brotherhood) and *"jejaring"* (networking) to share, support, and help each other. These are described as follows:

1.1 Accepting the reality of having HIV infection while *"pasrah"* (submitting self) to God.

All key informants understood that their present situation of having HIV infection is a reality or a destiny that has happened already. They could not escape or run away from the reality. In another words, they must accept it as it is, unless it would only prolong suffering resulting in frustration and despair. The term *"pasrah"*, which literally mean "surrender or submit", was used by the informants to describe their powerlessness against the reality of having HIV infection. The informants perceived that being currently infected with HIV infection was their destiny or fate. It must be accepted either as a consequence of their previous behavior or as a test of their tolerance. This is supported by one key informant's statement:

> *"Now, I couldn't do much further, but accepting the reality as it is. This is my destiny as a consequence of my previous behavior. I don't know how much of my life remains. Only one thing I care for myself by means of "pasrah" surrendering self to God and praying, I hope everything will be better." (K9)*

Another key informant stated that every single individual has his/her own destiny that has been determined by God before being born on the earth. However, form his perspective, one still has the opportunity to get a good fate if he/she works hard to pursue a good destiny while accompanied by prayer to God at the same time. By doing *"pasrah"* or submitting to God's determination and praying for a better life, the informants might gain psychological comfort and confidence to maintain their health for sustaining their life. As one key informant stated in the following:

> *"As a human being, sometimes my emotion is labile. Yet if I keep thinking of my condition, it would bother me so much which leads me to relapse on using the drugs. There is no point to deny this situation all the time because it has happened already. Everyone has their own destiny that is already decided by Allah. That way, just let everything go naturally. I "pasrah" to God's determination. Perhaps this is my lifeway set by Allah and it has to be like this. Nevertheless, I am working forward to restore health while praingy to Him in order to get a better life. Hopefully by these means, my destiny would change for be better. This is what caring means to me." (K6)*

1.2 Striving to maintain health by performing optimum *"ikhtiar"* (effort) and *"do'a"* (supplication)

All key informants expressed their insights about caring as performing optimum *"ikhtiar"* and *do'a* to restore and maintain health. The concept of *"ikhtiar"*, or literally meaning "genuine effort" to get something, reflected a deliberately strong intention and action to achieve or obtain something needed. However, since the informants believed that God has authority over everything, including health and illness, offering *do'a* (supplication) to request health and healing from God was supplementary. The informants realized that they were still confronting several issues related to HIV such as stigma, barriers to health care access, and lack of secure employment. These might reduce their optimism in sustaining life. In addition, deteriorating health conditions caused by HIV-related symptoms had hampered the informants' capability to achieve a better life. However, the informants learned to be able to pass these unpleasant moments successfully. They believed that frustration, despair, and hopelessness maintained continuously in their life could terminate their life. As one key informant expressed:

> *"Living with this illness is so terrible. My husband lost his job because his boss knew his HIV status, we often encounter financial problems to come to hospitals, some people here still think negative toward PLWH, and so on. However, I strongly believe that God has the best plan for every single individual including me. Our obligation is to perform "ikhtiar" and "do'a" in order to get help from God in healing this illness. That way I do not rely on only one method of treatment, I also tried other methods such as complementary therapies. To me, care means performing maximum "ikhtiar" as much as I can to keep healthy accompanied by offering "do'a"(praying) to God." (K8)*

From the key informants' perspectives, every single event occurring in this world has assisted them for learning the next steps of their life. They valued their health as an essential component to keep life going forward meaningfully. Therefore, striving to maintain health by performing optimum *"ikhtiar"* and *do'a* was conceived as meaning to care for one's self. One key informant stated:

> *"I believe that everything is under the control of God, even our disease and our body, if God wish to heal our body, He has power to do so, we just follow His commands and pray for the best wish for us. So to me, care may imply optimizing "ikhtiar" (effort) to search for best treatment for maintaining health while offering "do'a"(pray) to God." (K2)*

All family caregiver informants agreed that caring was optimizing *"ikhtiar"* (efforts) to heal the illness or maintain health. They believed that every single illness has its own medicines. It is an obligation of the sufferer or family to search for best treatment available. However, they considered religiously boundaries in searching for the best medication which recommended them to use lawful *(halal)* treatments. This meant whatever medications or treatment might be utilized they were allowable as long as they were permissible by Islamic law or God's instruction. One family caregiver said:

> *"I think caring indicated having optimum 'ikhtiar' for the best treatment of illness while offering "do'a" to God, because I believe that although medically impossible to cure the illness, if God is willing to cure the illness, it will be cured. I remember there is a teaching in my belief that every illness has their own medicines, so for AIDS also there must be a medicine, but we don't know yet. Perhaps one day, experts will find the medicine. We have to keep searching for the best treatment as long as "halal" or permissible by our belief." (G3)*

Similarly, all health care providers and community informants supported the concept of caring as performing *"ikhtiar"* (great endeavors) to maintain health or relieving illness and sufferings. They also emphasized the obligation of human beings to search for the best remedy in accord with proven knowledge and religious beliefs. As one health provider informant stated:

> *"I think caring also means putting 'ikhtiar' which means high efforts in searching for good treatments to maintain health. Yet, patients should consider searching for the best treatment which is reasonable or logically understandable." (G11)*

One community informant offered additional comments which incorporated religious perspectives that related caring as having the best *"ikhtiar"* and *"do'a"*:

> *"In religion we believe that every illness has its own medicines, but people have not discovered yet the best medicine now. So, if someone caring for who suffer from this illness this means having the best 'ikhtiar' or endeavor to find*

> *the best treatment which religiously acceptable, and also don't forget 'berdo'a' (prayer) because healing the illness is God's authority in our religious belief." (G19)*

1.3 Gaining blessing of God by doing *"kebaikan"* (good deeds) and worshipping

Six key informants acknowledged their previous behavior of injecting illicit drugs as a mistake that brought them to be infected by HIV. At the same time, they neglected their religious teachings to worship God. They perceived that being an HIV-infected person was the turning point to intensify worshiping God and doing *"kebaikan"* or good actions as compensation for 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 God for giving the time to return back into the right track as religion and society ordered. As one key informant said:

> *"Thank God for allowing me to remain alive though I have done many mistakes in the past time. I observed many of my friends have already gone and they did not have time to ask forgiveness and doing "kebaikan". So, to me caring could be meant as doing "kebaikan" and worship to compensate my previous mistakes and gain blessing of God. I believe that God is merciful and I hope He helps me." (K1)*

In addition, the informants believed that by doing good actions, God would forgive their mistakes and purify their sins. Thus they may enter paradise in the hereafter without any difficulties. An informant thought that doing good actions was also part of his responsibility to worship God following religious orders. This is supported by the following statements:

> *"Although we did many mistakes in the past time, I believed if we ask for forgiveness and compensate those mistakes by doing good actions, God will forgive and bless us and allow us to enter paradise in the hereafter. That what ustadz (religious teacher) taught to me. After a couple years living with HIV, I realized that I have to improve my worship to God. So I think, caring for self*

> *can be meant worshiping God and doing ‘kebaikan’ as much as we can to gain blessing of God. ” (K6)*

Three family caregiver informants supported this idea since they noticed their sons had serious faults that led them to become HIV-infected. Similar concern was also expressed by three community informants who highlighted the cause and effect principle that were widely believed to be social norms. Both family caregivers and community informants agreed that these faults had happened in a previous time that had already passed. Nowadays, they suggested doing the good things as compensation for previous faults as proof that they care for themselves. One family caregiver said:

> *“I am happy to see my son is getting better and turn his behavior to the right way. He looks seriously to balance his previous mistakes by doing something good. He performs obligatory prayer every day and starting to work as a freelance in a fence workshop. I think this shows he cares for himself.” (G1)*

This was also added to by a community informant who said:

> *“In our society we believe that one who was doing bad will get bad too. Yet, in the case of person with HIV, it has already happened in the past time. God is merciful if they are doing atonement and replacing their previous mistakes by doing good things. This implies that they are caring for themselves.” (G23)*

In the family context, all family caregiver informants expressed that providing good care for family members was their responsibility and could be categorized as worshipping God. They might sacrifice everything in fulfilling their responsibilities because they believe God will ask about it in the hereafter. One family caregiver said:

> *“Although my daughter has already passed away due to AIDS, I felt satisfied because I have done the best things in caring for her. Now, I return everything to God. I have fulfilled my responsibility to care for my daughter as much as I can. So, I hope it would not bother me in the hereafter when God ask me and I hope God accepts it as my worship to Him.” (G2).*

This idea also was reinforced by community informants who described that worshiping God was not redistricted to only performing rituals of religious practices. In Islam, they added, every single activity of a human being could be included as worship if he/she does these activities under fully consciousness of pursuing God's blessing. However, one community informant said that this type of worship was considered as general worship which had no special preconditions or clear religious guidelines. However, ritual worship, such as prayer and fasting was specific worship which clearly defined including given guidelines and conditions. This is supported by his following statement:

> *"Giving good care to people including persons with HIV could be categorized as general worship to God. Because in our religious teachings, every single activity is worship as long as it is done on the basis of pursuing His blessing." (G20)*

The conception of caring as a form of worshiping God was also expressed by three health care provider informants. They initially viewed caring as sincerely fulfilling our duty to provide good care, and three other informants then asserted that performing duties sincerely could be put forward as a type of worship from a religious perspective. Since all informants claimed they believed in God, they agreed that giving good care in caring for patients indicated they generally had paid respect to God. One health care provider informant stated:

> *"If I think deeply, it was also pity to them. They were victims of drug dealers who take benefits from them. After they got HIV infection, they suffered very much. So we should not add to their suffering by our negative attitudes. We must sincerely care for them, because it is our duty as nurses, and as a believer, I believe that it is a form of worship to God." (G17)*

1.4 Building *"persaudaraan"* (brotherhood) and *"jejaring"* (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 support 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)*

NGOs working in the HIV/AIDS field were not only facilitating HIV-infected persons to gather and help each other but also their families. The NGOs organized meetings and offered support for families of HIV-infected persons. This was mainly aimed at helping the families to share and learn from other in coping with various issues related to living and caring for family member with HIV infection. Family caregivers who joined the family self-help groups acknowledged the group as useful for sharing and exchanging knowledge and experiences. They also thought the group was beneficial to develop *"persaudaraan"* among family caregivers who have family member with HIV infection as it was recommended by their religious tenets.

Family caregivers recognized some issues could not be dealt with directly with the HIV-infected person because of unwillingness to disclose particular information.

In this case, the family caregivers might learn from others who have HIV-infected family members who have already disclosed about particular issues. For example, one family caregiver expressed her confusion regarding the cause of HIV transmission to her son when she knew her son was diagnosed as HIV-positive. Her son always kept quiet when asked about the cause of transmission. One day she was invited to attend family gathering of PLWH, and she learned many things including the possible cause of HIV transmission as experienced by her son. After she confirmed this with her son, she understood that her son was infected through shared needles when injecting drugs. From that time she tried to control her son's habits of using illicit drugs more strictly by observing behaviors indicating drug addiction, and watched the friends he was often with. As she expressed it in the following statement:

> *"In the beginning, it was quite hard to know how my son was infected by HIV. He always closed his mouth. One day, I was invited by an NGO to attend a meeting with families of PLWH. I learned that most of them said that their family members were infected through shared needles when injecting drugs and there were particular signs and symptoms that were similar to those experienced by my son. I confirmed this with my son and he accepted it. From that day, I strictly kept observing my son for particular signs and symptoms of drug addiction, including whom he was often with. Sometime I communicate by phone with other family caregivers to obtain advice about caring for my son. We felt alike "saudara" (brothers) who were concerned and helped each other in the group. I think it is a way we care for each other as ordered by our religion." (G3)*

2. Self-care activities by PLWH to maintain health and well-being

Three themes were extracted from the data related to self-care activities by PLWH to maintain health and well-being when living with HIV infection. These were: (1) promoting health and well-being; (2) relieving HIV related symptoms; and (3) reducing family care burdens. Each theme is described as follows:

2.1 Promoting health and well-being

Several caring activities or practices were carried out by key informants to promote their health and well-being. These were: (1) cleaning themselves from both visible and invisible dirt; (2) eating more for the body and giving food to the soul; (3) avoiding *"madharat"* (harm) by protecting themselves and others from further HIV transmission; (4) connecting themselves to God by praying more frequently; (5) gaining support by being involved with self-help groups; and (6) concealing HIV status thus "saving face" in relationships with others. These can be described as follows:

2.1.1 Cleaning themselves from both visible and invisible dirt

HIV has been perceived as a dirt illness due to the strong association with sexually transmitted disease as a result of misconduct according to existing social and religious norms. In addition, being a *"junkie"* (drug addict) was also perceived by the informants as living close to 'dirt' both visible and invisible. Visible dirt refers to physical appearance and was often identified as a characteristic of a junkie who commonly neglected personal hygiene and tidiness, was too lazy to take a bath, and even recklessly used shared unclean needles while injecting drugs. Invisible dirt was associated with negative thoughts that commonly appeared in a junkie's mind such as irritableness, telling lies, cheating, antisocial behavior, and irresponsibility. Six key informants acknowledged these thoughts frequently came up in their mind and drove their behavior. They claimed that being a junkie was like living in "the world of illusion". Every day they just thought how to get drugs to fulfill their addiction through various ways regardless of right or wrong. Their life pattern was a mess, and they cared little for the physical as well as social environment. Thus, being HIV-infected was viewed as being the time to care for one's self by cleaning the body and mind from these dirty practices. This could be done through leaving the drugs world totally and maintaining clean health. One informant said:

> *"I feel like living in a new life in the real world after quitting from drug use. Previously I felt my life was like under shadows of illusion which my mind was always filled by thinking about the drugs…I have my own world, the world of illusion, every times just thinking how to get drugs… I didn't care about my body's cleanliness, family, and environment, my hair was long and dirty, my life pattern was a mess, these made me tired and exhausted…the presence of HIV in my body has awakened me to the importance of maintaining health. Since that time, I decided to clean my body and my mind by stopping using drugs and caring for myself by being concerned more about cleanliness. Previously I was too lazy to take a bath, now I take a bath twice a day and feel it is helpful to cool down my mind against drugs addition." (K1)*

The term "clean" was also used in the 'drug user community' to refer to a drug user who has successfully ceased taking drugs. Becoming 'clean' from drugs was an incredibly difficult experience for some informants unless they had strong internal intentions and great support from outside. Two key informants were able to quit from drugs after several attempts coming and going from the rehabilitation centers. One key informant even intentionally surrendered himself to the police to be jailed in order to cut the connection with the drugs dealers. Two other key informants stopped using drugs due 'feeling extremely tired and exhaustion' resulting from the bad effects of injecting drugs on their health and well-being. Losing their health, property, and future hope had reinforced the intention of the informants to stop using drugs. One key informant said:

> *"Yeah …I stopped using drugs mostly because of exhaustion and tiredness that led to losing my health condition. It was useless if I worked hard, but the money was spent for nothing…I lost many things; health, money, my future,*

> *even my life was almost taken by overdoses unless God helped me through the health providers' assistance. Since that time, I committed to leaving drugs, I wished to be healthy, I had to clean myself from all visible and invisible dirt and come back to normal life." (K5)*

All key informants acknowledged that maintaining cleanliness was the essence of practicing a healthy life-style that was strongly recommended by health providers. Since it was also congruent with their religious beliefs with emphasis on cleanliness, they seemingly gained more confidence in maintaining self-cleanliness. Several measures were taken to maintain cleanliness such as taking a bath regularly, practicing ablutions *(wudlu)* before praying, cleansing the mouth and brushing teeth, washing hands after touching dirty objects or before eating, changing dirty clothes, and cleaning the house and environment. For invisible dirt, the informants tried to do *"istighfar"* (request God's forgiveness) and develop self-awareness through dialogue with family members, *ustadz* (religious leader), or HIV counselors. Interviews with family caregivers confirmed that those who had stopped taking drugs looked fresher, gained weight, were cleaner, and were able to perform positive behaviors. One family caregiver observed:

> *"His body looked cleaner and fresher than while being a drug user. Now, he is willing to practice maintaining cleanliness as he learned from his counselor. I and all family members always encourage him to clean himself not only physically but also his soul by reciting "istighfar". Thus he cares for himself." (G1)*

2.1.2 Eating more for the body and giving food to the soul

Informants perceived that food was not only needed for a healthy physical body but also for the soul. All key informants in this study expressed their difficulties in having sufficient income to meet their daily needs including food. This was supported by my observations about their living conditions. Most of the key informants' living conditions could be categorized as lower economic status. Only one of them were relatively well off with a regular income though they considered it was not enough. The key informants understood that food was essential to maintain health and keep away illness. However, since they could not afford to buy various foods, they had to be able to manage their available resources by mainly buying cheap food in large quantities and less quality. They perceived that eating more, particularly basic food such as rice, eggs, fish, milk and vegetables they would gain enough energy to fight the illness. One key informant stated:

> *"Of course, I think to be healthy one needs to take enough food as source energy to fight the illness. Although my family have not much money to buy quality foods, my sister always prioritized me and encouraged me to eat more. That way I try to eat as much of the food that is available though sometime it is only rice with salted fish." (K2)*

The informants added, 'food' for the soul was also important for maintaining physical and spiritual health. Since they realized that they had neglected the needs of the soul, their life became unbalanced which drove them to fall into the company of drug users. Other key informants who never engaged with either illicit drugs or promiscuity viewed food for the soul as being really important to strengthen their spirit in facing many difficulties resulting from being an HIV-infected person. All key informants referred mostly to religious practices as ways of feeding their soul such as performing fasting, reading the Qur'an, attending religious gatherings, listening to "religious lectures" through radio or TV, *dzikir* meditation, and reading religious books. These activities were considered by the informants as useful to promote spiritual well-being and to prepare themselves for facing the end of life. One key informant expressed her feelings regarding the efficacy of 'food for the soul' in dealing with difficulties related to living with HIV infection:

> *"I think it is very hard to live with this illness. Therefore, I have to keep my spirit up, don't let it go down and fall into bad things. I tried to feed my soul by attending religious teachings, praying 'tahajud' (mid-night prayer), and dzikir meditation. These helped me a lot to strengthen my soul in facing many difficulties." (K11)*

2.1.3 Avoiding *"madharat"* (harm) by protecting themselves and others from further HIV transmission

All key informants acknowledged that health care providers and NGOs had taught them the mode of HIV transmission. They therefore attempted to practice this knowledge in their daily life. Four men informants who had wives said that they always use condoms when having sexual intercourse with their wives, though some of them knew that their wives were HIV-positive too. Transmitting new types of virus meant giving *"madharat"* (harm) to their wife. This was also confirmed by their wives who were asked separately. They believed that condoms could prevent further HIV transmission to their spouses since they did not know exactly what types of HIV that each of them had. As one key informant said:

> *"Of course, I always use condom when having sex with my wife. Although it seems to be late because my wife was already positive, the counselor said that it is still necessary because it is possible I and my wife have different types of HIV. I don't want to make "madharat" to my wife by transmitting new type of virus from my body." (K10)*

The key informants stated that they maintained and used certain personal items, such as razors, nail clips, and tooth brushes separately from other family members. They understood that avoiding *"madharat"* (harm) to other family member should be taken into consideration. One key informant shared his vision:

> *"I have my own personal items for razor, nail clips, and teeth brush, drinking glass, yet for dishes and other utensils we share among family members. I think it is ok for me to prevent further transmission to other family members though they actually did not know that I am HIV-positive, except my mother and my wife. They are all my family. I shouldn't give "madharat" to them." (K1)*

Two key informants also expressed their concern about HIV transmission through blood due to injury or wounds therefore they prepared a set of basic first aid equipment such as bandages, sterile gauze, and antiseptic solutions. Six key informants who had offspring who were HIV-positive said that they needed to spend extra time to watch children while playing and be certain that the environment was safe. They did all things to avoid *"madharat"* for others due to HIV transmission as one of them claimed:

> *"I have a daughter who always wanted to explore everything surrounding her with her friends. I have to spend extra care to make sure her safety because I worry if she gets injury and bleeds which may carry and transmit the virus to her friends. My belief taught me not to make "madharat" to others. It is enough we have been suffering from this illness, but not others." (K3).*

2.1.4 Connecting self to God by performing *shalat* (prayer) regularly and *do'a* (supplication)

All key informants thought prayer was the main way to connect and communicate with God though some of them were still unable to practice regularly. *Shalat* (obligatory prayer) refers to a designed body posture movement combined with reciting certain prayer words. Whereas, *do'a* (supplication) refers to the words that are either pronounced or stated in the heart asking for blessing or any other particular thing to God. The informants realized that human beings have limitations including treating the illness, through connecting one's self to God by doing prayers in which they asked help from God to grant them healing, health and a better life. As two informants said:

> *"I strongly believe that God will help me, though the doctor said that this illness can't be cured completely, if it is God's will to cure… it will be cured and I will be healthy, so I just keep connecting to God by doing prayers more frequently and asking for healing and healthy." (K2)*

> *"Although this illness is incurable, we should not despair because the final decision is in God's hand, so I try to maintain connection with God by praying more frequently and particularly the prayer "tahajud" (mid night prayer) to ask for a better life for me and my son." (K11)*

The mistakes, bad things, or sins that had been done in previous times were considered as a psychological burden for informants. By doing prayers, they believed that God may forgive their mistakes and release their burdens. This is supported by the following statement:

> *"I have done bad things in the previous time that led me to get HIV infection. Previously I rarely did prayers to God. Now, I am trying to get close to God by doing prayers more frequently. I hope God is willing to forgive my mistakes." (K10)*

2.1.5 Gaining support by involvement with self-help group

HIV and AIDS have been considered as a complex disease which impacts on multiple facets of life. Many people living with HIV infection experienced stigmatization, marginalization, and discrimination by the society where they live. By the facilitation of NGOs', they attempted to form self-help groups as a forum to share knowledge and experiences in dealing with various issues related to living with HIV. However, as a further development, some self-help groups might be established independently from NGOs while some were still under the management of NGOs. Ten key informants in this study expressed their participation in self-help groups though some of them did not involve themselves intensively. Two key informants mentioned that they had never attended the meetings due to the distance involved and had no money for transport. Those who actively participated in the groups thought that it was useful because they gained knowledge, experience, and support from others who had similar problems. They expressed that this was a way of caring for themselves as one of them put it:

> *"When I firstly knew my HIV status, it was a really stressful moments. Luckily, one of my friends took me to a self-help group nearby here. This opened my eyes that many other people also encountered similar experiences as me. So, I did not feel alone again. I learned a lot from them and it was really helpful for me." (K8)*

My observation when attending a meeting of the support group suggested that the meeting's participants looked free to express their feelings in the forum. They warmly greeted and shared their experiences with each other while enjoying some jokes and laughter. Occasionally, they invited expert speakers such as doctors, nurses, or psychologists to talk on particular topics. At the end of each session, the group leader led the other members to pray together for their health and better life.

2.1.6 Concealing HIV status for "saving face" in relationship with others

The remaining strongly perceived stigma towards HIV and AIDS held by all key informants has led them to keep quiet about their HIV status, except to particular persons who they trusted. The key informants and family caregiver informants assumed that other people might lack proper understanding about HIV and AIDS which might put PLWH as sources of "gossip". It might cause the PLWH to be avoided or rejected by people in the community. Therefore, they prefer to hide their HIV status, or otherwise talk about another illness such as TB, diarrhea, lymph nodes enlargement instead of HIV. One key informant stated:

> *“My neighbors here just knew that I had “bungkul” (lymph node enlargement), I thought it was not necessary to tell the truth because when people knew one of my friend died because of AIDS, people look scared, and became gossips…it is easy to spread the information to all people, so people may avoid or reject me. I do this to save my face and my family’s reputation.” (K6)*

On the other hand, PLWH and family realized that they could not live without any interaction with the community, relatives, friends, and neighbors. They concealed their HIV status to preserve their dignity, saving their face from *“aib”* (disgrace or embarrassments) in order to maintain good relationships with people, and avoid rejection or discrimination by other people. Therefore, they thought it was better for people in the community not to know their HIV status. Thus they could maintain good relationships and avoid unexpected reactions from people. One family caregiver informant reported:

> *“In this house, only me, as his mother, and his wife know about his HIV status. People around here, even his brother, don’t know. I think it is better to keep quiet to avoid negative attitudes from people. It is necessary to save our face because people may think our family is bad because of having a family member infected by HIV. I think it can be considered as “aib” for my family, so it is not good to expose this to other people.” (G1)*

2.2 Relieving HIV related symptoms

Along with fluctuating health condition, the key informants experienced various symptoms and co-morbidity related to HIV and treatments. Most of the symptoms were weakness, losing body weight due to persistent diarrhea, or chronic coughing due to lung infection. Skin rashes, black marks on the skin, itching, and oral infection were reported by the informants. Besides using modern medicine to relieve symptoms, they also attempted to find strategies or techniques including integration of complementary or alternative therapy. Four types of caring activities emerged from the data for relieving HIV related symptoms. These were: (1) practicing self-healing; (2) using complementary or alternative therapy; (3) seeking modern health care assistance as needed; and (4) maintaining ARV adherence as prescribed. They are described as follows:

2.2.1 Practicing self-healing methods

The key informants who had mild to moderate symptoms tried to find their own ways to relieve the symptoms before seeing health care providers. Two key informants shared their experiences in relieving their numb feet by soaking the feet in warm water for 15 to 20 minutes. Self massage was utilized by several key informants to relieve their muscle pains. Taking a regular rest between activities was mentioned as a way to reduce fatigue during activity. Morning sunbaths were considerable useful to relieve itching skin for those who did not have skin rashes according to a key informant. Having a good sleep was expressed by three informants as a strategy to relieve headache and tension. Light walking around the house was also practiced by several key informants to overcome their fatigue and boredom. The following statements supported the above explanations:

> *"Previously I had numbness in my feet after taking ARV medication. My feet soles looked pale and felt cold, so I soaked them in warm water. It worked and gradually the numbness went." (K1)*

> *"I do sunbathing in the morning to relieve my itching skin and to warm up my body. I prefer to do that rather than using lotion or powder which makes my skin sticky. It was not so bad and quite helpful for mild itching." (K4)*

> *"I just take a walk around here in the afternoon to eliminate fatigue and feeling boring caused by staying whole days in this room. It was good for exercising my feet." (K6)*

2.2.2 Using complementary/alternative therapies

The uncertainty with the efficacy of modern medicine in eradicating HIV has made people living with HIV look for alternative therapy. It was mostly cheaper, easily available, and had less side-effect than modern medicine though its efficacy was also questionable. Four key informants shared their experience in using alternative therapy for relieving HIV related symptoms. For example, one informant preferred to use *jamu* (mixed-herbs) to relieve stomach pain and nausea resulting from ARV side-effects. Other key informants had used different treatments including: immunity booster supplement products to enhance body immunity; massage for relieving muscle pain; modified their diet by consuming fish food products; soaking in natural hot springs to relieve itching skin; using urine therapy to increase immunity and appetite; and visiting folk healers who they believed had supernatural powers to eliminate the disease. Each informant used one or more than one type therapy depending on his/her need and preference. Occasionally they felt better after using the therapy to relieve particular symptoms. However, some symptoms still remained though they used more than one type of alternative therapy. The informants believed that these were only one alternative way to gain health besides using modern medicines. This is supported by the following statements:

> *"I felt nausea and my stomach looked like squeezed at the time of deteriorating my health condition due to HIV infection. My mother persuaded me to drink this jamu. It was much better after several times." (K4)*

> *"I have been trying to use urine therapy as a complement to taking ARV. I usually take about a spoon of morning urine and drink it. Initially it was yucky, but I forced myself because I wanted to get better, and then the result was good. My body weight increased 2 kg within a month. Looks, my dress seems to be not fitting again with my body." (K11)*

> *"I noticed something unpleasant with my body. My weight dramatically decreased from 40 to 32.5 kg in a couple of months, rashes and eruptions appeared on my skin. I was easily getting sick on the following days such as ears infected by worms, eyes infected, itching, and diarrhea and losing my weight. I was taken to a natural hot spring which located in the neighborhood this district. It worked for me temporarily, particularly relieving skin rash." (K2)*

2.2.3 Seeking modern health care assistances as needed

Not all HIV-related symptoms can be managed by the key informants themselves. All key informants have experienced various degrees of physical symptoms from mild to severe that drove them to look for health care facilities and seek medical assistance. Three types of health care facilities that were commonly visited by the informants were community health centers, hospitals, and private clinics. Seven key informants were initially taken to health care facilities by their family after developing serious symptoms such as diarrhea, coughing, headache, skin rash, and infection of the sexual organs. Two of them were even unconscious when sent to hospital. Eight key informants just knew that they were HIV-positive after being admitted to hospital. As one key informant said:

> *"At that time, I often got headache that gradually increased its intensity. One day when I was in the bathroom, I suddenly I fell dawn unconscious. My mother took me to the hospital looking for help and shortly days after I was informed that I was HIV-positive." (K10)*

Five key informants actively sought medical assistance by themselves after knowing their spouses were diagnosed as HIV-positive. One of them knew her HIV status after having HIV screening for applying for a job. The company rejected her when she was known to be HIV-positive. She then came to the community health center to seek advice. Among twelve key informants, four of them were facilitated by an NGO to get health care access due to financial constraints. Eleven key informants perceived that modern medicine was useful to control HIV related symptoms though they had to deal with the side-effects of the medicines. Even though they knew that modern medicine, particularly ARV, does not completely cure HIV, they believed that it was one of the best choices currently available for prolonging their life. This is supported by the following statements:

> *"After my husband died because of AIDS, my niece took me to a laboratory clinic for getting HIV test. Several months afterward, I developed many terrible symptoms such as skin rush, diarrhea, and ear and eye infection which brought me to a hospital. Luckily there was a relative who help me to get government health insurance for the poor, so I could get hospital treatment free, otherwise I could not go because I had no money." (K2)*
>
> *"Although I knew that the modern medicine cannot completely cure the HIV illness, this is the best option that is available now. So we were religiously encouraged to use it as an effort to maintain health while we are praying hopefully that the best medicine would be discovered some day. That way I go to the hospital clinic every month to obtain ARV and examine my health." (K11)*

2.2.4 Maintaining ARV adherence as prescribed

The availability of ARV which is free of charge for PLWH has given a significant hope for PLWH to live longer. The government has been subsidizing ARV since 2004. The price per package per month for the first-line fixed-dose combination (lamivudine, zidovudine and nevirapine) produced by a state-owned pharmaceutical company is US$38. In the beginning, the government provided a subsidy of US$20 per month, so PLWH had to pay US$18 per month per package.

Then, in accord to the policy 3 by 5 launched by WHO, the government increased the subsidy to cover all costs of first-line ARV regimens. Therefore, PLWH might get free ARV, but they still have to pay for diagnostic tests and other medication. At the time of this data collection (2008), there was a big issue circulating among PLWH that the government considered removing the subsidy for ARV procurement. As a result, ARV was scarce in many centers in Indonesia. PLWH usually got ARV for a month's treatment, and since that policy applied they only got a week's course of treatment. Many PLWH, NGOs, and HIV activists insisted that the government guaranteed ARV availability. One key informant expressed his concern about the possible effects of ARV scarcity on PLWH's life as he said:

> *"We, PLWH and family, were very concern and stressful when we heard that ARV stock has been diminished, because we are highly dependent on the drugs. If the drugs supply was stopped, it means no hope to sustain life." (K12)*

In the beginning, ten key informants in this study had been undergoing ARV medication. However, three of them had dropped out from ARV from over six month ago due to not tolerating the side-effects and financial constraints. One key informant has not yet met the criteria for ARV, and another key informant was reluctant to take ARV due to negative perceptions towards HIV side-effects. One informant who reluctant took ARV stated:

> *"This is the box of my pills, it consists of more than five types of pill including for my lung TB, fungi on my tongue and skin herpes. So if I still have to take ARV, I am afraid that these will accumulate the toxins in my body." (K4)*

Dealing with the side-effects of medications was viewed as an unpleasant experience. These included nausea, vomiting, headache, insomnia, and feeling depressed which lasted from one week to one month. They strove to pass this stage by various attempts including asking advice from health care providers, obtaining support from family or support groups, and finding their own way to cope with their problems. Maintaining adherence was initially perceived as a continuingly difficult experience due to dealing with the side-effects. Yet as the time passed, they learned to adjust and accommodate as part of their daily life. Various tips were applied to keep taking ARV regularly without missing such as using alarm clocks, family reminders, and modifying pill boxes and containers. Feelings of boredom were sometime encountered by particular key informants. This might have led them to discontinue or drop out from medication if they had not been able to handle it, as experienced by one key informant in this study. An informant shared her strategy to maintain ARV adherence as follows:

> *"At the beginning of taking ARV medication, I experienced nausea, dizziness, and was unable to sleep well at night. So it was really unpleasant and I almost stopped it, yet I kept in mind that I have to live for my children. I assumed the pills to be vitamins or part of the food that I have to consume daily. Gradually I became more tolerance of the pills and it is now alright" (K2)*

2.3 Reducing family care burdens

Living with a complex chronic illness such as HIV has imposed a significant burden of care on the person with HIV her or himself and her or his family. The key informants in this study understood this situation, and therefore some of them shared their ideas on caring practices with regard to reducing the burden of family care. Two particular caring practices emerged from the data including: (1) performing the routine activities to fulfill his or her role; and (2) earning more *"rizki"* (income or livelihood) with the *"halal"* way.

2.3.1 Performing the routine activities to fulfill his/her role

Ten key informants in this study stated that they tried to distract their mind from continuously thinking about the illness by making themselves busy in doing routine work. Those who were housewives they spent much time each day looking after children and doing household tasks such as cleaning the house, preparing food, laundering, washing dishes, and guarding the shop. They said that they did not have much time and could not leave children, even for a while, for doing physical exercises. They felt it was helpful for them to keep physically active instead of spending specific time doing physical exercise. It was also useful for them to distract their thoughts from continuously thinking about their illness. One informant said:

> *"My daily time is almost spent doing my routine house work such as going to the market to buy food, preparing food, cooking, cleaning, washing, visiting my brother who is sick, and taking care of my children and my sister's children. It was good to entertain myself instead of thinking so much about the illness." (K2)*

The informants believed that it was useless to think much about illness because it had happened already. It just made them stressed which might lead to lowering their health condition. In contrast, two housewife informants showed lack interest in doing either physical exercises or housework because they lived with their mother who did everything for them. The male informants mostly spent their time working outside of the home in looking for livelihood for the family. One informant said:

> *"I have a family who need food, dress, etc. Evenif I have no permanent job I have to find the way to earn some money for me and my family. 'Alhamdulillah' (Thank God) I was accepted by a fence workshop to work*

> *freelance to find customers who want the fences made. I try to keep busy by performing my role as a subsistence earner." (K1)*

2.3.2 Earning more *"rizki"* (incomes) with the *"halal"* (lawful) ways

Eleven key informants stated that they did not have regular incomes for paying for their daily lives and their families. Their main source of income was usually support from their parent or sister or brother. Eight key informants lived with their parent though seven of them were married. In this society, those who are married usually live separately from parent and are independently responsible for their life. The main reason for those who remain to stay with parents was the lack of capability to earn an income for the family since they were sick. However, after their health condition improved, they attempted to find some ways to earn income and live independently from their parents. One key informant shared his opinion regarding his responsibility to earn an income for his family:

> *"As a head of a family, I have responsible for earning 'rizki' with the 'halal' ways for my family as taught by religion. My wife is responsible for looking after me and our son, that way I called her to return back and lived with me since she left me after knowing I am HIV-positive. Now, I have a small business in running this shop. So, even though I am HIV-positive, I am still able to earn some money for my family." (K10)*

During my observations, five key informants were selected to receive a capital grant from the government through NGO assistance. Four of them started up a stall at their home which sold household gas bottles, food, drinks, and other daily basic goods' Another informant was running a cell phone business. By doing so, the informants showed responsibility for themselves and their own family as was socially and culturally appropriate. From the informants' view, living with long term chronic illness, such as HIV, involves extra expenses for continuing medication and treatment.

It was not convenient to always depend on parents or relatives. They believed that God had sent down *"rizki"* (livelihood) for every single life on earth. Human must search for it and pick it up by the *"halal"* (legal ways) or in accord with the law of religion and the state. This was supported by the following statement:

> *"I need money for schooling my son and of course for my health care services. That way I have to find some ways to earn money. I believe that God has prepared "rizki' for every single thing in life. Our obligation is to pick it up with the 'halal' way. Thank God, I got a grant from government, so I can run this small business though it is just starting, I hope it can help me and my family to run our daily life." (K11)*

Caring and Support for PLWH Provided by Family, Health Care Providers, and Communities

Caring in this study is viewed as a cultural phenomenon that is shared, learned, and passed on to the next generation among members of the cultural group. Thus caring is embedded in the way of life of people who surround PLWH who are both professional and lay carers. In a culture where kinship and family cohesiveness are more apparent, caring for sick family members is more likely to become a major responsibility of the family. Meanwhile the sick persons prefer to be cared for in the environment in which the family is physically present and close to them. Three categories or themes emerged from the data and each theme consisted of several caring practices for PLWH. These were: (1) physical care; (2) emotional care; and (3) spiritual and social care. Physical care is the most common caring activity described by all group of general informants, while emotional, spiritual and social care are more likely to be described by family and community groups. Each theme is described as follows:

1. Physical care

Physical caring was mainly addressed at maintaining the physical health of PLWH. Four caring activities were identified that reflected physical care: (1) nourishing the PLWH; (2) reminding PLWH to take medication on time; (3) maintaining the cleanliness of PLWH and the environment; (4) and encouraging ways to manage symptoms. These are described as follows:

1.1 Nourishing the PLWH

All family caregivers observed that providing adequate food or nourishment for PLWH was important to gain and keep health. Although many caregivers encountered financial constraints in buying the best quality food, they tried to make food available within their maximum capacity. There was a cultural tradition in the society where the informants live whereby priority was given to providing good food for sick persons according to the capability of the family and relatives. Families might tighten their budgets for other things in order to obtain the food that was needed by the sick. One family caregiver, a 70 years old father, shared his experience in obtaining the food for PLWH though this was hard due to financial constraints:

> *"My son used to be live in the city with a lavishl lifestyle. He mostly ate expensive foods. He was rarely willing to eat our foods when he got sick and return back to us who live in the village. Anyway, because he is our son, we always try to meet whatever food he wished though it was expensive for us. We save money from buying other things and put priority for our sick son." (G8)*

Other general informants from health providers and the community agreed that prioritizing nourishment for the sick was important to be healthy. In the health care setting, health care providers always encourage PLWH to take good nutrition. Taking adequate nutrition would help to increase the body immunity of PLWH. People in the community also expressed similar ideas regarding the importance of food for recovering from illness. In some areas when a community member was sick, neighbors and relatives came to visit while offering some food for the sick. One community informant shared in the group discussion:

> *“The sick person usually experiences a bitter taste in his/her tongue, so in our tradition when we visit the sick we offer some food that easy to digest such as “agar-agar” (soft cake) and fruits. It is important to give enough nutrition to the sick, and it was recommended by our religious teaching to help the sick.” (G18)*

Nourishing PLWH, particularly those who were sick, reflected a form of caring activity that was provided by people surrounding PLWH. Although some constraints existed, the family caregivers showed their genuine efforts to provide the best food as wished for by the sick person.

1.2 Reminding PLWH to take medication on time

This caring activity was pointed out by all family caregiver informants. Family caregiver informants expressed their experience of supporting HIV-infected family members to adhere to their medication as prescribed. Some family caregivers noticed that PLWH seemed to be bored and would miss taking ARV for some days. The family caregiver and other family member would then have to keep motivating the PLWH and encourage them to adhere to medication. One family caregiver’s wife, said:

> *“Sometime he almost misses the pill while asleep or looks like he wants to skip the pills, so I must wake up him and remind him to take the pills. I am very concerned of his missing pills. I don’t want him to get trouble in the next days if he misses the pills.” (G4)*

In health care settings, all health care provider informants said that they were always concerned to remind PLWH to take medicine regularly and with the right dose. One of them also said that the patient was required to come along with at least one family member or caregiver for counseling before commencing an ARV course. All key informants, especially those who were undergoing ARV or TB medication, acknowledged the role of the family in reminding them to take medication on time. Another family caregiver stressed the implication of missing pills for PLWH for the next treatment:

> *"I always remind him to take pills when I am available at home, when I go to work his wife always reminds him to take ARV medication. I told him that he must adhere to take the mdication on time as the doctor prescribed because if you miss, the doctor said he must change the medication and it looks more complicated." (G1)*

1.3 Maintaining the cleanliness of PLWH and the environment

All family caregivers confirmed that maintaining the cleanliness of PLWH and the environment was important and greatly affected the health of PLWH. It was also recommended by religion. Although some of them realized that they could not do anything much with the environment because their living conditions were poor, they could still find the best way to provide a supportive environment for PLWH. For example, a family caregiver expressed her concern when her house did not have enough sun lighting since it was located in the middle of crowded housing area. She had learned that it might effect to the health of her family. I noted that her family, with seven family members, lived in a-5x6m2 house which was a non-permanent construction. The walls and roofs were made from woven bamboo. The inside of house, especially the bedroom, looked dark with little ventilation or air circulation. Houses in this area were connected closely to each other. I had to pass a small channel that could only be passed by walking to reach the informant's house. The family caregiver also said that her late husband and daughter who were HIV-infected suffered from TB. Her daughter had dropped her TB medication and recently she was undergoing second line TB treatment. The family caregiver showed her concern for maintaining cleanliness and environment for HIV-infected family members:

> *"It is difficult to get sunlight in this house, but I couldn't do much to repair this house. Instead of doing so, I suggested to my daughter to get out from home and take a sunbath. I also clean up her room every day. I washed her clothes and dishes. Even when she got sick, I bathed for her. That was all done to maintain cleanliness for her because I believed that it is important for her health and religiously recommended." (G2)*

The notion of maintaining cleanliness for PLWH was also reinforced by health providers and community informants. In health care settings, health providers maintained the cleanliness of PLWH by stressing that PLWH should wash their hands before eating or after touching something dirty. For those who were unable to bathe independently, the nurse provided bathing or coached the family caregiver to do so. They also explained that their beliefs inspired them to maintain cleanliness. One health provider informant stressed:

> *"This is our duty to maintain the cleanliness of our clients including PLWH. However, it is depending on the level of dependency. We might assist totally, partially, or just educate the family to provide hygiene for PLWH. I think beside as it is useful for health, it is also strongly recommended by Islamic teaching which is held by the majority of clients here." (G13)*

Community informants supported this idea of maintaining cleanliness as a religious practice though they highlighted not all people have full understanding or were able to practice this teaching very well. Cleanliness, according to community informants' perspectives, seemed to be more physically oriented. In fact, according to their beliefs, it should cover both physical and spiritual matters. Therefore, they offered the term *"pembersihan"* (purification) which refers rto removing 'dirty' objects' in the sense of both 'physical' (visible) and the 'soul' (invisible). Physical cleanliness could be achieved by cleaning the body and environment regularly. Thus, soul purification could be done by asking forgiveness both from God by saying more *"istighfar"* (forgiveness) and from ones who have been oppressed. The community played a role in maintaining the cleanliness of community members by providing infrastructures such as clean water, public bathrooms, and toilets for those unable to build these in their own homes. In the context of maintaining cleanliness for PLWH, one community informant shared his perceptions:

> *"We did not do directly in terms of maintaining cleanliness of PLWH because their family is most suitable to do so. However, we might help them by assuring that every community member has access to clean water, clean environment, and proper bathroom and toileting. We do cleaning of our neighborhood environment together at least once a week. In my opinion, clean doesn't mean only physical that we can see, but also our soul needs to be cleaned by saying "istighfar" and asking forgiveness to ones who has been hurt as our religious teachings addressed." (G23)*

1.4 Encouraging ways to manage symptoms

Living with chronic illness such HIV required the informants to deal with long-term signs and symptoms. The symptoms that were encountered by PLWH were diarrhea, breathing difficulties, coughing, fever, pain, fatigue, itching skin and mucosal infection, and losing weight. Family caregivers, in particular mothers, were often the first ones asked by PLWH for advice when they encountered particular symptoms. The next persons usually asked for advice were friends, wives and spouses, NGO staff, and health care providers. All family caregivers confirmed that they initially utilized symptoms management methods based on their experiences and 'knowledge' gained from older people or relatives before contacting health care providers. For example, one family caregiver shared that she advised her daughter to take *"jamu"* (mixed herbs with turmeric as the main ingredient) to reduce stomach discomfort. Another family caregiver encouraged and facilitated PLWH to utilize natural hot springs to reduce itching skin symptoms. This was demonstrated by a key informant:

> *"At the time I experienced my skin had rashes and was itching. My family did not have enough money to see a doctor, so they encouraged and took me to a natural hot spring nearby this district. I went there several times and it was quite helpful. Unfortunately, it was quite far away from my home, so I could not go more often to the place." (K2)*

The interviews with family caregiver indicated other methods that were commonly used to manage symptoms. These included: applying cold applications to reduce fever; drinking warm water for relieving coughing; massage for relieving pain; eating meals with a fishy odor such; as snails, shells, and small fishes. These were done to increase immunity and reduce birthing difficulties. In some cases, family caregivers might suggest that PLWH utilize some medicines that were commonly available in the street shops for alleviating diarrhea, fever, coughing, and pain. However, they expressed some concerns about using certain common medicines which could have a worse effect on PLWH. They usually sought advice from NGO staffs (counselors or case managers) or health care providers prior using the drugs.

From the perspectives of health care provider, caring practices for PLWH also included encouraging ways to manage symptoms. Four health provider informants highlighted this notion as they found many of the PLWH developed chronic symptoms that needed to be managed either by themselves or with assistance from health care providers. The types of management strategies for symptom have to be addressed in accord with the major prevalence of symptoms that most PLWH encountered. One health care provider informant expressed her experience in caring for PLWH:

> *"When I care for PLWH in the community health center, I noticed some of them developed symptoms such as muscle pain, numbness, and fatigue. Beside providing medication, I taught them how to manage these symptoms by themselves. For example, I taught them how to manage their daily activities to reduce fatigue, and how to do simple massage to relieve pain. This is part of our caring." (G10)*

2. Emotional care

Caring for the emotional or psychological aspect of illness was viewed as a very important aspect to help PLWH cope with their stressful moments. Two of the caring activities that emerged from the data included: (1) comforting PLWH by offering *"nasihat"* (advice) and *"melipur"* (consoling); and (2) being with and helping PLWH. These themes are described as follow:

2.1 Comforting PLWH by offering *"nasihat"* (advices) and *"melipur"* (consoling)

This starts with learning to accept the HIV diagnosis and confronting the various symptoms resulting from HIV infection. These were perceived as stressful moments which featured by uncertainty, hopelessness, and despair. In this situation, the family demonstrated a significant caring role to comfort, support, and assist HIV-infected family member to boldly face the situation. All family caregivers expressed their experience when being with HIV-infected family members in dealing with stressful moments. Some of them used religious teachings and practices such as *nasihat* (advices), to *pasrah* (submit) and *sabar* (patience), or performing *do'a* (supplication), *dzikir* (meditation), or reading the Qur'an as ways to gain comfort. A mother who was taking care of her son infected by HIV pointed out:

> *"A few days before he passed away, he confessed his mistakes for not obeying his parents' instructions so far, that way he got the illness as a consequence… and he felt guilty and emotionally depressed…gently I embraced him and advised him… I said you must be 'sabar' and 'pasrah' to Allah (god)…no other is the best way except you submitted everything to Allah, because it has already happened. I always forgive you, even if you don't ask it, just do do'a (prayer) and 'dzikir' to Allah in order to gain His forgiving and blessing…these things that I could do to comfort him while he was facing emotional depression." (G6)*

Other methods to comfort PLWH when they encountered emotional problems were by consoling or entertaining them. This was aimed at distracting their thoughts from thinking too much about the illness. One family caregiver expressed the local term of *"ngabrangbrangkeun (Sundanese)"* which is equal to *"melipur (Indonesia)*" which is comparable to the notion of consoling:

> *"…her emotion has been unstable since she knew her status of HIV-positive and quite often of getting sick. As her mother who cared for her very much, I tried to "ngabrangbrangkeun" (console and entertain) her thoughts with nice words in other to make her feel comfort, such as 'oh my dear, don't worry too much, you are still young and we all love you, just let it go. See your son, he is very cute and he needs your presence to care for him. I hope by doing so it can comfort her." (G5)*

Five health care provider informants emphasized that comforting PLWH was essential particularly when provide counseling and it must be integrated in caring practices for PLWH. They pointed out at least three types of counseling should be incorporated, namely: counseling for HIV testing (VCT=Voluntary Counseling & Testing, and PITC=Provider Initiative for Testing & Counseling); counseling adherence; and family counseling. The informants recognized the need for health care providers to be equipped with comforting skills to improve their caring practice particularly in counseling. This is supported by the following statement:

> *"I think providing comfort is an important part of our care skills for PLWH. Many PLWH encountered emotional problems particularly when they knew the result of HIV-positive. That way, we must be able to comfort them while giving counseling by assuring that we are ready to help them. Unfortunately, not all nurses were equipped with this skill, particularly those who have never been trained about counseling techniques." (G13)*

Community informants offered additional perspectives regarding providing comfort for PLWH. They assumed most PLWH hid their HIV status due to the emotional burden of being HIV-positive causing "embarrassment". It was possible because of being labeled with a "moral illness" or "sinner illness" which might be perceived by people generally. In this regard, people in the community might help PLWH or whoever is suffering from the illness to relieve the emotional burdens by comforting them. Several methods might be offered such as giving motivation, supportive words, *nasihat* (advices), offering *do'a* (supplication), and showing attention by visiting the sick person either in their home or hospital as ordered by religious teaching. One community informant suggested:

> *"I think we can understand if PLWH don't want other people know their status because of emotional burdens such as 'feeling embarrassment'. They may think of it as a moral or sinner illness. Actually our religion taught us to care for the sick persons including those who suffering with HIV by providing comfort and encouragement. We may give them 'nasihat' to leave their negative behaviors and motivate to have spirit for sustaining life, or at least offering 'do'a' or other supportive words to encourage their hearts." (G23)*

2.2 Being with and helping PLWH

Being with and helping PLWH refers to physically presenting one's self and being ready to help PLWH as required. This theme was expressed by all family caregiver informants particularly when PLWH need help. For example, at least one family member, such as a husband, wife, mother, father, sister, or brother, is usually involved in accompanying a PLWH when visiting health care service or being admitted to a hospital. One family caregiver who patiently accompanied their HIV-infected family member to go to health care facilities shared their insights:

> *"As his condition was becoming worse, I took him to the community health center. The doctor said that he had to have VCT, unfortunately the service is not available in the health center then I sent him to the public hospital for further health assistance. I always accompany him when visiting health centers as well as when being admitted to hospital. By being with him or physically present with him, and helping him when he was in the critical moment, I think I have fulfilled my care and responsibility to my son." (G1)*

Health care provider informants confirmed that caring for PLWH needs devotion, strong courage and the intention to be with and help the PLWH. The latter may be due to feeling fear of contagion as well as the label of 'moral illnesses' attached to this illness. They recognized that not all health care providers are currently equipped to provide good care for PLWH due to their lack of knowledge and skills. They also have personal fears about safety and protection. Therefore, the willingness to be with and to help PLWH without feeling fear and prejudices has become an essential aspect in practicing care for PLWH:

> *"I demonstrated to my colleagues that being with PLWH and helping PLWH was essential in caring for PLWH. It implies being able to physically present and being ready to help PLWH when they need it. Yeah, those who work particularly in the ward and are rarely exposed to the updated knowledge and skills about caring for HIV/AIDS patients, still think it is a scary illness. They are scared of transmission, particularly when self-protection equipment is not sufficient. Therefore, it needs great willingness about being with PLWH and helping PLWH as a form of caring practice for PLWH." (G16)*

Community informants added that being with and helping PLWH in terms of accompanying and helping and supporting PLWH was important. This was also stresed by several community elements such as NGOs and community health care volunteers. NGOs played important roles in helping and supporting PLWH to gain access to health care and to be accepted by the family and community. One community informant who was also an NGO manager who worked for PLWH shared his experience in helping PLWH:

> *"We have been working for many years to reach the IDUs in order to get HIV test and proper health care services. This also included advocacy to family, community, health providers, and other related institutions. We show pity to them. Many of them are young people. In some cases, they were rejected by the family or community, even health providers. As an element of the community, we are here to be with them and help them to be able to cope with their HIV-related problems and prevent further HIV transmission." (G25)*

3. Spiritual and social care

Caring for spiritual and social aspects of PLWH were viewed by family, health provider, and community as an integral part of caring for PLWH as a whole. Three themes emerged from the data: (1) encouraging and facilitating to perform *"ibadah"* (worship); (2) accepting PLWH as a community member equally to others; and (3) performing rituals for dying and death PLWH. These are described as follows:

3.1 Encouraging and facilitating to perform *"ibadah"* (worship)

Family caregivers noticed that their HIV-infected family member had neglected some aspects of religious practices or *"ibadah"* (worshiping God) while they were drug users. This moment was viewed as a great opportunity for PLWH to improve their *"ibadah"* for compensating for previous neglect. However, the family could not enforce much with the PLWH since they were adults who must be responsible for themselves. The role of the family was to give encouragement and facilitate the PLWH in performing *"ibadah"* based on their intentions and willingness. One family caregiver expressed her visions in encouraging and facilitating them to perform *“ibadah”* for PLWH:

> *“He was actually a good boy before involving in drug use. He used to perform “ibadah” such as shalat (obligatory prayer), go to the mosque to learn Qur’an, and doing fasting. He completely left the activities after engaging in drugs. Now, I encourage and facilitate him to do more “ibadah”, because this is a great chance given by God to compensate for previous neglect. However, he hasn’t done it regularly, but I look for some improvement from him compared to previous times.” (G3)*

In health care settings, health provider informants acknowledged the important of encouraging and facilitating PLWH to perform *“ibadah”* as a mean to fulfill spiritual needs. Most health providers did not have enough confidence to encourage and guide clients in performing “*ibadah*”. However, a few of them were still concerned about this need and tried to incorporate the family in ensuring that the spiritual needs of clients have been met. Six health provider informants who participated in group discussions shared their experiences in encouraging and facilitating PLWH doing *“ibadah”*. One of them stated:

> *“I often encourage PLWH to do “ibadah” in accord with their belief as much as they can. For those who Muslim which is the same belief with me, at least I can encourage to perform shalat (prayer) and/or do’a (supplication) because it is important to strengthen the spirituality of the client when facing difficulties. This is also an integral part of our nursing care for PLWH.” (G17)*

Community informants reinforced the idea of encouraging and facilitating PLWH to do *“ibadah”* in accord with their belief. Although seven of them have no direct experience in dealing with PLWH, they agreed that PLWH need to be supported and facilitated to do religious practices since they have neglected this. One community informant stressed that the root of problem of young people engaged with drugs was lack of ‘*iman’* (faith) that led them to neglect religious teachings and practices. Therefore, people need to encourage and facilitate them to get back into the right way by performing *“ibadah”* or religious practices. One community informant who was a religious leader stated:

> *“It is important for us to encourage and facilitate HIV-infected person to perform “ibadah” by following God’s orders and avoid God’s restrictions. Because I believe that only by improving ‘iman’ (faith) and taqwa (consciousness), we can handle this HIV problem successfully.” (G19)*

3.2 Accepting PLWH to be a community member equally to others

This theme was mainly expressed by community informants. All of them concurred that PLWH should not be neglected or discarded by the community because it violated humanity. Even though some of HIV-infected persons were likely to have engaged in deviant behaviors, informants said they were not in a position to judge persons’ behaviors. Let God determine the appropriate reward or punishment for such persons. As believers we just obey God’s orders to do good deeds for all fellow humans, especially those who are sick or suffering. Accepting and treating PLWH as equals to others would make them comfortable and might make them cooperate to stop further HIV transmission. A community informant observed:

> *“I think as a form of caring for HIV-infected persons is to allow them to stay and live together in our community. They are our people who being sick. We should accept them as equal to other members as long as they can behave in accord to our community norms. We are not in the position to judge their behaviors, just let God determine the reward or punishment for their behaviors. We just follow the God’s command to do good deeds to all people. If we treat them well, they will cooperate with us so HIV further transmission could be controlled.” (G18)*

Other community informants stressed the right of PLWH to be accepted in the community. They have abandoned all the negative behaviors that they have done such as taking drugs or engaging in illegal sex. They also emphasized that accepting and treating others equally reflected the teachings of their religion. According to a community informant:

> *"So, as long as they became a good member of the community and leave all of unlawful behaviors far away, we can accept them in community equal to other members. This is strongly recommended by our religion who taught us to treat people equally regarding their social economic status or types of illness." (G23)*

Most key informants did not think that disclosing their HIV status would make a better relationship with people in the community. They knew that people in the community knew they were suffering from a particular illness such as pulmonary TB, diarrhea, or other chronic illnesses, rather than having HIV. Two key informants expressed their appreciation for the acceptance and assistance of people in the community which made it possible for them to get health care services. One key informant shared her impressions with the acceptance and assistance of people in the community though some of them already noticed that she was HIV-positive:

> *"I appreciated the people here who accept me and treat me equal to other community members though some of them knew my HIV status that I got from my late husband. I think it because previously I was known as a good member in this community and I often help people here when they need. I thank so much to the neighborhood leader and the community health volunteer that have assisted me in getting access to health care services. Since they knew I have no money to come to hospital, they arranged me 'health insurance for the poor' and send me to the hospital." (K2)*

3.3 Performing rituals for the dying and dead PLWH

During the data collection period, three family caregiver informants experienced grieving moments due to the passing away of their HIV-infected family member. They shared a meaningful experience in caring for the dying and dead PLWH. One family caregiver talked about her experience and feelings when caring for her dying son in her home. Her daughter was in an apathetic condition and refused to eat any foods for several days. She was very depressed with her husband who left her for another woman. Physicians in the hospital have given up and said there was no further treatment for her condition. But day to da, she spent time on her bed in her home and her condition continuously deteriorated. All family members and relatives then gathered and performed a ritual *"yasinan"* (recitation *"surah Yasin"* [the name of a chapter of Qur'an]) and *do'a* to give strength to the sick in order for them to die peacefully. This was described by the family caregiver who was the mother of the daughter infected by HIV:

> *"I have done many things for my daughter in order to improve her condition. Yet, she seemed to be hopeless and did not want to eat any foods, even just open her mouth for a spoon of water. Doctors said that they could not do anything much, just take her back home and provide anything that she wished to make her be happy. So, I invited all family members and relatives to gather and performing the ritual "yasinan" and do'a to help calm her mind and she was able to pass away peacefully." (G2)*

Two other family caregiver informants expressed their experience in dealing with the village community's response towards the death of a person with AIDS. In the beginning, no one in the community knew much about the diagnosis of AIDS of the dead. However, someone unintentionally disclosed the information and made people in the community noticed that the family member died because of AIDS. Thus, when the death body arrived, here no one willing to come close and care for the dead body due to their feeling of fear. The family was shocked by the response of people in the community at the time. However, with the assistance of NGO staff and local religious leaders the family tried to explain and persuade people in the community that AIDS was not something to fear. It could be prevented and controlled. This work seemed to take effect and people in the community gradually understood and were willing to participate in performing rituals for the dead person. These included bathing the dead, wrapping-up the dead body, prayer, and sending the dead body to the cemetery to be buried. One family caregiver informant provided insights into performing rituals for the dead:

> *"After people here understood, some of them were led by the religious leader in performing rituals for the dead according to Islamic teaching including bathing the death body, wrapping up the death body using white plain fabric, prayer for the dead, and burying in the cemetery." (G6)*

Cultural Beliefs and Values Associated with Caring for PLWH

Several cultural beliefs and values associate with caring for PLWH were highlighted by key informants and general informants. This was also confirmed by my observations. These can be categorized into two major categories including: (1) cultural beliefs and values facilitating caring; and (2) cultural beliefs and values impeding caring. These are described as the follows:

1. Cultural beliefs and values facilitating caring

This refers to values and or beliefs that facilitate caring for PLWH. These beliefs and values mostly derive from religious beliefs that have become part of the local cultural beliefs and traditions. Five themes emerged from the data related to cultural belief factors that can promote caring. These were: (1) "*iman*" (faith); (2) "*persaudaraan*" (brotherhood); (3) "*sabar*" (patience); and "*tabah*" (hardiness or endurance); (4) "*kesetaraan*" (equality); and (5) "*kebersihan*" (cleanliness). These are described as follows:

1.1 *"Iman"* (faith)

Faith has been perceived by the informants as a fundamental belief that provided great confidence in dealing with life's difficulties. All key informants agreed that living with HIV infection has posed many difficulties in life. This was compounded by other factors such as poverty, joblessness, and poor education; these overwhelmed PLWH by multiplying hardships in life. My field observations showed that ten informants had insufficient living condition. They were not living in their own house, but either in their parent's or sister's house, or a rented house. Five of them only occupied rooms with small space. Lack of income and secure employment has forced them to tighten all expenditures including those for daily basic needs and health care expenses. The phrase *"life is so terrible"* was frequently expressed by key informants and this represented their feeling of suffering in dealing with daily life.

In some cases, the situation may lead to frustration, hopelessness, and even suicide. Fortunately, ten key informants in this study were able to handle these difficulties because they still maintained *"iman"* (faith). Faith or strong belief in the power of God's help has served as buffer to stand up when facing life's difficulties. One key informant shared her experiences in utilizing her faith to strengthen her power to sustain life:

> *"Living with this complex illness combined with economic difficulties, being a widow, and having small kids who need support was really terrible. If I thought too much, maybe I will become crazy or suicidal. It is very hard to live in this way. Fortunately, I still have "iman" (faith). I strongly believe God will help me, if not now perhaps tomorrow or in future. I also believed that after hardships, easiness will come subsequently. That is our religion taught us. This faith has driven me to care for myself in order to sustain my life." (K11)*

The significance of faith in promoting caring for PLWH was also indicated by family caregivers:

> *"It is very hard to me for have a daughter suffering from this illness. Since my husband passed away a couple years ago, I have to earn money by serving neighbors here who wished to wash clothes or doing housework. I don't have enough money to send my daughter to hospital. It is only "iman" or belief in God that empowered me to care for my daughter and to face the many difficulties in life." (G5)*

Health care provider informants acknowledged the religious perspective concerning *"iman"* in promoting caring for PLWH. They understood that the essence of *"iman"* was comparable with the term "spirit" in their professional terms. In their vision, *"iman"* was viewed as a driving force to be responsible for maintaining life through performing good care. One health provider shared her vision about *"iman"* and its association with caring:

> *"It is clear for those who believed in Islam like us to see "iman" or "spirit" in our professional term to serve as driving force to be more responsible in respecting and maintaining life. One way to do so is by performing good care for life." (G9)*

In addition, community informants reinforced the association between *"iman"* and caring for life through Islamic perspectives. They believed that health and life were an *"anugrah"* (endowment/award) given by God that needs to be given thanks for and maintained. Caring for health may reflect the proof of responsibility towards the life given by God. Therefore, maintaining *"iman"* was equally important as maintaining life or caring for life according to Islamic beliefs and perspectives. One community informant who was also a religious leader stated:

> *"Life and health is an "anugrah" given by God, we should thank for that by caring for health and fulfilling life with good things in accord with God's*

> *rules. This can be done if we have "iman"; it means that we believe in God and actualize the belief through our actions and behaviors in daily life. In case of PLWH, although medically the illness is incurable and life seemed to be diminished, if they have "iman" in their heart, they must devote optimum efforts to care for their life. So, maintaining "iman" is equally essential with maintaining life." (G23)*

1.2 *"Persaudaraan"* (brotherhood)

The key informants acknowledged that the spirit of brotherhood played a significant role in caring for PLWH. The term *"persaudaraan"* (brotherhood) in this context represented the feelings of being like a brother towards other people. This covers love, empathy, compassion, loyalty, care, willingness to share, support, and help each other. It was not restricted to blood ties, personal backgrounds, social hierarchy, or economic status. The key informants developed a spirit of brotherhood among themselves. This was triggered particularly by having commonality in term of the experience of living with HIV/AIDS as well as dealing with HIV/AIDS-related issues. They appreciated the work of NGOs which facilitated them to meet each other, share with each other, and help each other. Many PLWH took advantage of the existence of self-help groups that were established by PLWH. Some PLWH who had problems with their own family, such as being neglected by their family, preferred to stay with their PLWH peers who lived separately with their family. One key informant who had joined a self-help group expressed her feelings of being involved in the group:

> *"It was suggested by a health provider to come to an NGO. Previously, I had never known what the NGO was doing and I think it is only me who gets this serious illness. Amazingly, the NGO staffs were warmly welcoming me and offered me to join the self-help group. It had opened up my eyes that there were other persons also suffering from the illness, but they still looked cheerful, calm, and easy going. I learned many things from them and we felt*

> *like brothers or sisters for each other. Sometime we eat together, hang out together, even cried together when one of our members went earlier. Overall, the sense of brotherhood that we developed was really endorsed by caring among us." (K11)*

Family caregiver informants offered additional perspectives about the spirit of brotherhood among PLWH. Four family caregivers who were often involved in gatherings or families affected by HIV stated that the sense of brotherhood also existed among them. It was brought about not only because of there being commonality among of them, but it was also based on their religious beliefs which encouraged them to help and support each other. Family caregivers were aware that the family was the basic unit in the society where all family members grew and developed. Families should provide supportive environments for growing and the development of all family members. In this sense, family caregivers perceived that the spirit of brotherhood was an extension of the kinship in families. This served as reinforcement for caring among family members on a small scale, and in society in a larger scale. One family caregiver shared this:

> *"I have had chances to attend gatherings of family affected by HIV several times. The atmosphere was good. We shared knowledge and experience each other. Some particular issues that we were difficult to inquiry from HIV-infected family members, we might share and find the solution together. We felt emotionally close each other, not only because of having similar problems, but also basically because it was encouraged by our beliefs. The spirit of brotherhood like that should actually be started in the family environment to reinforce caring among family members. Yet, sometime we missed it and our family members tried to find it from others." (G3)*

Health care provider informants noticed the brotherhood spirit among PLWH or IDUs was greater than in other populations. This was evidenced by the many self-help groups that grew up by being facilitated by NGOs working in the HIV/AIDS field. This was understandable since they exposed many common issues such as social stigma, legal aspects, employment, and accessing health care services. They needed to unite their power and capabilities to face the issues together. From the health provider informants' perspective, the spirit of brotherhood could also be applied to health providers who enhanced the quality of caring for PLWH. By looking at PLWH as brothers who needed help, health providers were expected to be able to eliminate the negative feelings and prejudices shown towards PLWH, In turn this would improve caring for PLWH. One health care provider informant stated:

> *"I think the spirit of brotherhood that is more apparent among PLWH could be applied to our colleagues as well. For those who are still reluctant to care for PLWH and have negative attitudes, just think what if it happened to our own family? See them as our brothers who need our help to eliminate the negative feelings. It would be useful to improve the quality of our care." (G14)*

Community informants expressed real examples of the implementation of the spirit of brotherhood among community members including assisting the PLWH in their community. From the community informants' perspectives, the spirit of brotherhood which was rooted in religious beliefs should be applied to particular people with the same beliefs regardless of their geographical origin, race, ethnicity, social economic status, and political vision. The implications of such values for all people who have the same belief (Islam) might help them share, help, support, and pray for each other. Offering prayers for other believers including PLWH was viewed as one example of implementing the spirit of brotherhood from an Islamic perspective. In addition, there were others aspects of this spirit of brotherhood based on bonding and similarity, such as geographical origin, ethnic background, professional background, and common organizations. In this type of brotherhood, people might share many things as they preferred, except prayer. These types of brotherhood were significant to facilitate caring for other. However, according to the community informants' views, religious brotherhood should be put higher than others since it was linked directly to God. God has set down the rules to be applied and followed by all believers. To implement the spirit of brotherhood, four community informants proposed examples of community participation in care for PLWH. These were "*warga perduli AIDS*" (residents' care for AIDS), NGOs, volunteering to support HIV prevention, and care programs. One community informant shared her experiences involved in community activities as a form of brotherhood spirit in caring for PLWH:

> *"I remember when I hung around the neighborhood, I found one man who looked very weak and very sick. He lived in very poor conditions. I asked him why you did not go to health center. He said that he did not have enough money, even for daily food. We could not arrange health insurance for the poor because he had no ID card due to temporary resident here. I was touched and I came to the neighborhood leader. I asked his permission to do fund rising by circulating the charity box to neighbors. Thank God, we were able to collect some money and send him to a health center. People here still have the spirit of brotherhood, but sometimes there is need for someone to trigger it off. This was useful to facilitate PLWH getting access to health care." (G26)*

1.3 "*Sabar* (patience) and *tabah"* (hardiness/endurance)

The term "*sabar"* is equal to "patience", whereas '*tabah"* was comparable to "hardiness" or "endurance". However in the context of coping with difficult situations, both concepts were used together to describe the quality of the ability to experience difficulties without complaining or showing emotions. Both key informants and general informants articulated the essence of "*sabar* and *tabah"* in dealing with illness, pain, suffering, and other difficulties. They considered that one who has high levels of *"sabar* and *tabah"* in dealing with difficulties would imply showing more caring for him or herself. In the context of living with HIV infection, *"sabar* and *tabah"* or stoicism was important to enhance levels of tolerance toward chronic symptoms as well as long-term dependency on ARV medication. This represented a psychological condition which may provide a better place for developing caring and well-being. One key informant shared her visions regarding applying *"sabar* and *tabah"* in caring and living with HIV infection:

> *"Living with HIV infection imposed multiple chronic problems and required long-term adherence to ARV medication. It is so boring if we don't face it with "sabar and tabah". Some friends stopped taking medication because they could not tolerate the side-effects of medication. So, "sabar and tabah" would increase our level of tolerance in dealing with many difficulties resulting from HIV-related problems." (K10)*

Family caregiver informants supported the notion of *"sabar* and *tabah"* as essential factors associated with caring for PLWH. In the family caregivers' perspective, *"sabar* and *tabah"* could also be implied in the context of the family of HIV-infected persons. The burdens of care and multiple impacts resulting from having a family member infected by HIV have imposed significant hardships that need to be offset by utilizing *"sabar* and *tabah"* in coping with the hardships. Therefore, family caregivers proposed that *"sabar* and *tabah"* could be a way of coping with particular difficulties which reflected the outcome of caring. One who has *"sabar* and *tabah"* in facing difficulties was more likely to be able to cope with the difficulties and show positive outcome of caring:

> *"When my son was approaching die, his condition was very poor and his watery fecal continuously coming out contaminated to almost entire his body. He was suffering and in here (at home) no one wished to get close to him. As his father I reflected to myself, oh my dear son this condition was very hard*

> *not only for you but also for me, both of us need to have "sabar and tabah" in facing this situation. I believe if we received this situation with "sabar and tabah", God will help us to remove all difficulties. This really worked in empowering me to cope with such a situation." (G8)*

Health care provider informants reinforced the potential association between *"sabar* and *tabah"* and caring for PLWH. They thought that *"sabar* and *tabah"* in dealing with HIV-related problems could be the foundation to establish self-care behaviors such as maintaining hygiene, managing symptoms, taking long-term medication, and seeking health care assistance. Additionally, *"sabar* and *tabah"* may also serve as foundation to develop harmony among mind, body, and spirit. As one health care provider informant put it:

> *"I think "sabar and tabah" for PLWH in dealing with various HIV-related problems is very important as a foundation to build self-care behaviors. It is impossible for them to perform the long-term self-care practices without having "sabar and tabah". Cultivating "sabar and tabah" in their hearts would facilitate harmony in mind-body and spirit." (G13)*

Similarly, community informants provided a deep insight in seeing *"sabar* and *tabah"* from religious perspectives and its relation to care for PLWH. All community informants agreed that living with HIV infection was not easy, especially for those who have never engaged with particular risk behaviors such as a wife infected by a husband. They recalled it as a huge test from God that needed to be accepted with *"sabar* and *tabah"*. Having *"sabar* and *tabah"* in carrying out all types of life tests was essential to successfully pass the tests and gain the blessing of God. In the context of having serious a illness, such as HIV, *"sabar* and *tabah"* should not be meant passively by receiving the illness without making any efforts. It implied devoting optimum efforts to search for healing. However, in many cases the healing was usually a complex process which could take a long time, involve a lot of resources, and required several procedural steps. Unfortunately, the results of healing also did not always come as precisely as expected. Therefore, *"sabar* and *tabah"* may serve as a buffer in going through the journey of being a HIV-infected person. Thus, caring for life or caring for health reflected the efforts that have to be carried out to go on this journey successfully. One community informant felt:

> *"I can imagine how difficult it is to live with HIV. It is a great test from God that needs to be received with "sabar and tabah". However, those who suffer are required to keep effort in searching for healing though sometime take long process and get unstuffy result. Therefore, in our belief we are just encouraged to make optimum efforts, for example by means of caring for health, and praying to God for the best result. So, "sabar and tabah" can be a buffer in carrying life with the illness, while caring for health is an effort to keep life moving forward." (G26)*

1.4 *"Kesetaraan"* (equality)

People living with HIV infection often perceived themselves as a marginalized population with unequal rights in accessing public facilities compared with the general population. This perception was also held by seven key informants in the initial phase of HIV infection. However, when the time passed, they learned and observed in this study setting. Thus in terms of public health facilities, the situation has been much better than in other settings, which indicated that more people and health providers were able to accept PLWH as being *"setara"* (equal) to other people. Key informants stated that equality was very important for them in terms of providing equal chances to access and to utilize public facilities. As the equality was assured in the health care service, PLWH would feel confident to use the health care services. Conversely, when discrimination or inequality against PLWH existed in the health care service or other public spheres, the PLWH were less likely to use health care services or participate in public events. Key informants viewed ‘equality’ as an assurance which allowed the PLWH to have access to all public service facilities including ‘care’. One key informant stated:

> *“…in the community health center near here, the service for PLWH is good. We are treated “setara” with other patients. The providers are skillful and attentive to all patients. That is why many PLWH come to the center to get health care services…” (K5)*

Family caregivers added that treating PLWH equally to others also applied in the family context. They said that although the HIV was contagious and many issues surrounded the illness, the family still had to look after their HIV-infected family member because it was an obligation of the family. Treating all family members equally, in terms of providing love, compassion, support, resources, and help, was considered as a cultural and religious responsibility of the family. However, in the case of family members infected by HIV, the family should also take into consideration the suggestions given by health care provider to prevent HIV transmission to other family members. The family caregivers thought that by treating the PLWH equally, or with no discrimination, it would comfort them and facilitate family caring for PLWH:

> *“I care my children equally including my son who suffers from HIV because it is my responsibility as taught by religion. I don’t separate him in term of using eating utensils, food, bed linen, and the toilet, except for personal hygiene tools such as razors, tooth brushes, or something that is expose to his body fluid as I was told by health providers when I took my son to the hospital. I think my son understood and could accept this, and he looked fine with the way the family cared for him.” (G1)*

Health care provider informants were aware of the significance of treating patients equally without discrimination. They noticed some of their colleagues who treated HIV patients unequally to others might do this because of lack of preparation or training, particularly if this took place in the past when HIV cases were scarce. However, by exposing nurses more to HIV-related training and supervision, the cases of discrimination would decrease and caring would improve. One health care provider informant made this clear:

> *"Yes, in the past, some colleagues had not been well prepared yet to care for PLWH. Yet nowadays, I think the situation of care is better, many health providers treat HIV patients equally and as a result many PLWH come to our clinic to get heath care." (G17)*

Community informants reinforced the association between *"kesetaraan"* and the outcome of caring for PLWH in the context of community settings. The informants suggested that if people in the community still discriminated against PLWH and did not give equal them equal access to public facilities, including job opportunities, the PLWH would have more burdens in their life. This might lead to frustration and suicide. Suicide is a big sin that is strongly prohibited by religion. If this condition took place, it meant people in the community had indirectly contributed to the process of suicide and shared responsibility this great sin. Therefore, ensuring equality, fairness, and justice in every aspects of life was stressed by religion to maintain caring and harmony among community members. One community informant who was health volunteer commented:

> *"I think as people in the community we should understand the feelings of PLWH. Don't put additional burdens on them by treating them unequally to other members. If they get frustration and suicide because of our actions, it means we should share responsibility of their sin, because it was prohibited by our religion. We should accept them equally with other members, so it means we carie for them." (G18)*

1.5 *"Kebersihan"* (cleanliness)

Key informants have learned that people living with HIV infection were vulnerable to other communicable illnesses since their body immunity was reduced. Thus they understood that many communicable illnesses were transmitted through agents which were mostly attached to the dirty objects. Therefore, maintaining *"kebersihan"* was extremely important for them as a way of caring for themselves. The informants gained this knowledge mostly from health care providers or NGO counselors as part of health education topics related to healthy life styles for PLWH. Although in reality not all key informants, particularly those with IDU backgrounds, were able to practice it very well, the informants attempted to implement their knowledge in their daily lives. Two key informants tried to link the importance of cleanliness with the Islamic tenet which stressed maintaining cleanliness, particularly when Muslims want to perform ritual worship to God.

> *"Health providers educated me to maintain "kebersihan" to promote healthy life. If I am dirty, many illnesses will come along with dirt. So, maintaining cleanliness could be a basic practice of caring. I think it is fine, because our religion emphasizes much on this value of cleanliness, particularly when we want to perform ritual worship, such as "shalat". Unfortunately, some friends still have less commitment to practicing it." (K3)*

Family caregiver informants acknowledged the importance of cleanliness in caring for or maintaining the health of PLWH. Some of them also learned from health providers when they saw health providers. The caregivers' role was particularly focused on facilitating clean environments, preparing clean food and water, and reminding or assisting PLWH in maintaining personal hygiene. The informants asserted that cleanliness was an integral part of caring practice which was significant for health. As the informants also believed in Islam, they associated the importance of being clean with their religious teaching. One family caregiver shared her experience in maintaining cleanliness for her HIV-infected daughter:

> *"I attempt to practice what health providers taught about cleanliness. I remind my daughter to take a bath, clean her bedroom, preparing clean foods, etc. Sometimes she looked lazy, even to wash her dress, I did it for her. To me it is ok because it is basic practice to care for health, and religiously encouraged. Yet, she is supposed to be able to do by herself as long as she is healthy." (G5)*

Health care providers have been trained within the biomedical framework of disease, this resulting in a belief in cleanliness that influenced the care of PLWH. The health provider informants also realized that Islam which is believed in by people in the setting, valued cleanliness as a prerequisite prior to performing ritual worship. They also incorporated the value of religion into their practice when caring for PLWH. One health provider informant said:

> *"When I delivered health education or counseling for Muslim PLWH and families about healthy life styles, I tried to link it with their religious belief which emphasizes cleanliness. It makes sense because some people feel more confidence to practice something as it is congruent with their beliefs." (G13)*

Community informants offered additional reasons for the importance of cleanliness in caring for PLWH and its relationship with Islamic religious belief. From their perspectives, the value of religion could be a strong motivating factor for the believers to practice cleanliness since they believed that God loved those who kept clean both *"lahir"* (visible things) and *"batin"* (soul/invisible things). *"Lahir"* refers to something that is physically tangible such as body, house, and environment, while *"batin"* refers to things that physically intangible such as soul/mind, heart, thought, and intention. All those things need to be cleaned regularly in order for *"lahir* and *batin”*.to be healthy. Dirty *“lahir”* could be easily recognized by other persons, whereas dirty *“batin”* one would know her or himself, unless it was manifested in her or his behavior. A simple example of dirty *“batin”* is *“iri hati”* (jealousy). This refers to feeling unhappy when someone is successful in life. Therefore, cleaning *“lahir”* could be performed by removing all dirty things from visible objects, while cleaning *“batin”* could only be done by doing *“pembersihan jiwa”* (self-purification). Self-purification could be performed by asking forgiveness from God *(istighfar)* and/or someone who has been oppressed or harmed. It is done byperforming ritual worship such as *shalat* (obligatory prayer), reading the Qur’an, *shaum* (fasting), hajj (pilgrimage to *Makkah*). In addition one should keep concentrating the mind, soul, thought, heart, and intentions on God while performing activities in daily life. In the context of caring for PLWH, the community informants proposed both types of cleanliness should be taken into consideration. One community informant thought:

> *“I think HIV illness is not only about physical illness but also mental behavioral. So, caring for those people should include both physical and mental behavior. In terms of cleanliness, it should also cover “lahir and batin”. If they have clean “batin” they should not engage in such risky behaviors because it violated the religious norms.” (G19)*

2. Cultural beliefs and values impeding caring

This refers to cultural values and beliefs that may inhibit caring for PLWH. Two themes emerged from the data. These were: (1) covering *“aib”* (disgrace); and (2) misconceptions about *“nasib”* (destiny). These are described as follows:

2.1 Covering *“aib”* (disgrace)

For some informants HIV and AIDS were perceived as a “dirty illness” which was linked with “immoral behavior”. Therefore, having HIV or AIDS might be considered as an embarrassment. The term *"aib"* represented the embarrassment resulting from such behavior that makes other people lose respect. It is translatable to "disgrace" according to the Online Cambridge Advanced Learner's Dictionary (www.dictionary.cambridge.com). Covering up disgrace or *"menutup aib"* in the informant's term, was aimed at protecting dignity or 'saving face' by the HIV-infected person him or herself, the family, and society. All key informants and family caregiver informants stated that they preferred to conceal their HIV status to people generally since they were not sure about people's attitudes towards PLWH. If they exposed their status, it meant they exposed their *"aib"* which might cause other people to lose respect for them. This can also inhibit a person from accessing health care services due to feeling embarrassed if they meet someone else from their community who will then know their HIV status. A key informant expressed his concern about this issue:

> *"This is "aib", other people should not know about my HIV status, only me, my mother, and my wife who know about this. If other people know, they will mock me and become a gossip topic that may easily spread out in our community. So, it is better to cover this "aib" to save the reputation of myself and my family. That is why I don't want to come to the nearby health center here for my health problem related to HIV, because I worry if people here recognize me as an HIV-positive person." (K10)*

This was reinforced by family caregivers who said that it was not necessary to expose the HIV status of their family members to the general public since it might impact on their family's dignity. Family caregiver informants also associated the obligation of covering *"aib"* with the religious tenet which emphasized protecting the *"aib"* of oneself as well as other people. Talking about *"aib"* of particular people was considered a sin because it caused someone who had *"aib"* to feel uncomfortable or embarrassed. In case of PLWH, family caregivers also preferred to avoid mentioning the HIV diagnosis of the HIV-infected person when talking with other people. Even they attempted to minimize having contact with surrounding people including visiting health care services unless it was necessary. The informants noticed that this attitude could possibly impede health care providers or other people who were concerned about HIV prevention and care since they might not know directly where the PLWH were. One family caregiver said:

> *"Nobody around here knows about my son's HIV status. It is an "aib" that should not be exposed to the general public. I think it is encouraged by my belief to protect the "aib" of self as well as other persons, because it is sinful. As a consequence, it may inhibit people who wish to care, to find the PLWH in the community, but I think it is ok to take my son to health center, if necessary, instead of officers visiting us because people would inquire what was wrong with our family." (G3)*

Health care provider informants offered their opinions about relations between the beliefs of covering *"aib"* with care for PLWH. In the informants' perspective HIV/AIDS should not be perceived as an *"aib"* or something to make HIV-infected person embarrassed. The informants added that nowadays everyone might have an equal chance to get HIV regardless of their previous behavior. Generally people need to be persuaded to have positive perceptions and attitudes towards PLWH. Thus PLWH should bravely disclose their status so health providers or outreach workers could easily find them and take them to health centers. One health care provider informant thought:

> *"Nowadays everyone have equal chances to get HIV, so actually PLWH should not perceive HIV as an "aib" and there is no need to worry much about disclosing their status. But, firstly we have to persuade the general public to have positive perceptions and attitudes toward PLWH. So if they can disclose this and people know, it would be easy to reach them and bring them to health care services." (G9)*

Community informants offered opinions about the importance of covering *“aib”* in the context of religious tenets and community living. The belief of obligations to cover disgrace was aimed to protect human dignity and to maintain harmonious relations among community members. So those who unintentionally did mistakes which caused *“aib”* should not feel guilty any longer or insecure about living in the community. However, those who committed mistaken behavior have to self-reflect and self-correct. Therefore, covering *“aib”* could be applied for a period of time while the -person concerned is undertaking self-correction for their mistakes. In the context of PLWH, community informants perceived that those who have never engaged in immoral behaviors should not consider HIV as an *“aib* or worry about disclosing their status. People would see it was as *“musibah”* (ordeal) or *“ujian”* (test) rather than an *“aib”*. One community informant observed:

> *“I think not all people infected by HIV have engaged in immoral behavior, some of them got it from husbands. So they should not perceive it as an “aib” and should not worry about disclosing their status. Yet for those who have engaged in immoral behavior, it could be considered as an “aib” and they have to correct themselves. Our beliefs indicate that “menutup aib” should be applied in the proper context to protect human dignity and should not impede caring for those who need. If they cover their HIV status, how can people help them if people don’t know.” (G23)*

2.2 Misconception about *“nasib”* (destiny)

The term *“nasib*” could be translated to “fate” or “destiny” and means the things that will happen in the future. Since the informants believed that everything that happens in this world is based on God’s will, including their life as an HIV-infected person. Thus they might perceive that being an HIV-infected person was their fate which was impossible to change. As a result, they might just surrender to their fate without making any serious efforts to change their condition into a better condition. The Online Cambridge Advanced Learner's Dictionary defines the term "fatalism" which is described as "The belief that people cannot change events, particularly the bad ones which have happened or will be happening in the future, and the events cannot be avoided" (www.dictionary.cambridge.com). In this context, three key informants thought they could do nothing and had given up due to perceiving their huge burden of being an HIV-infected person. They dropped out from ARV medication and two of them passed away after collecting the data was collected for this study. One key informant shared her feelings regarding the burden of being HIV-infected:

> *"Everything looked dark to me. I am much stricken with this reality. My husband left me after he infected me. My mother has to work hard for me and my son because my father has died five years ago. I can do nothing except stay at home with my weak condition. I stopped taking ARV because I had no money to visit the hospital. Sometime I want to die soon. Maybe it is better for all people here. I only "menyerah ke nasib" while waiting for death." (K7)*

Pessimistic feelings include feeling bored and skipping taking ARV medication if there is no family supervision. There may be non-compliance with treatment and care prescriptions, and verbal or written expressions about willingness to die. One family caregiver described such experiences:

> *"I unintentionally found a diary book of my son when I cleaned his bed. I found a piece of poetry entitled "Awaiting for a death" written by my son. In the following day, I confirmed to my son about the meaning of his poetry. He said that it represented his feeling of hopelessness about his condition. I said to him, you should not be "menyerah ke nasib". It is not the end. God still gives time to do the best. So, don't think like that. It is not encouraged by our religion to be hopeless." (G3)*

Health care provider informants also explained their experience about noticing some PLWH showing fatalism or pessimism about their condition of living with

HIV/AIDS. They hypothesized that it was because of misconceptions about the concept of *"nasib"* (destiny or fate). Some PLWH perceived destiny as the end of their present condition and thought they had no more options or actions to change their present condition. As a result, they only passively accepted the situation without putting much effort to changing the situation. One health care provider informant shared her vision:

> *"I sometime asked HIV-infected person when opening the result of HIV tests in the post test counseling 'How do you feel if your lab result is HIV-positive?', some of them said 'it maybe nasib, my end of life has to be like this'. I said no, 'nasib' doesn't mean the end, you are still alive and have time to do something. Only God knows exactly the end of life of every person. This misunderstanding may impede the care for such people." (G9)*

Community informants expressed similar notions as health provider informants and emphasized how perceived destiny should not lead to being fatalistic. Being fatalistic meant they did not care for themselves because they had no strong intention to search and utilize the best method to overcome their critical situation. A community informant stated:

> *"It is debatable to describe one who is infected by HIV as a "nasib" meaning nothing can be changed because of incurable illness. Actually, we believe that every illness has its own medicine. But medicine was not always in the form of drugs. It could be something else that caused healing. So, PLWH should see it as a challenge to change their condition instead of "menyerah ke nasib" or being fatalistic, because it may inhibit care for themselves." (G25)*

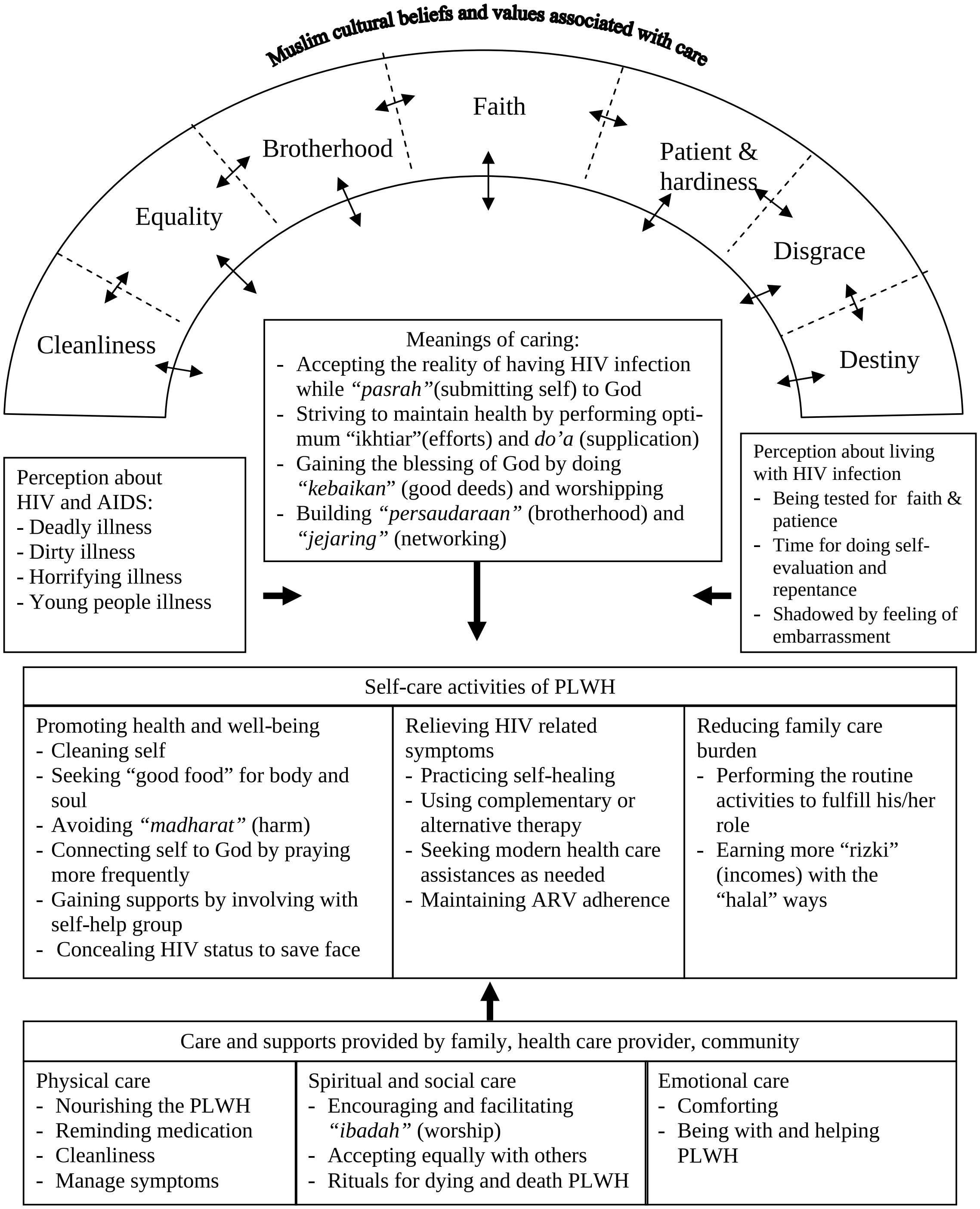
From the informants' perspective, it seemed that being fatalistic was caused by misunderstanding the destiny that might hamper any efforts to improve the present condition. This included seeking health care assistances to maintain their health status in order to prolong life.

Summary of Findings

The informants in this study showed that their worldview was influenced by Islamic cultural beliefs which therefore influenced their caring for PLWH. They pointed out their perception about HIV and AIDS as: (1) a deadly illness; (2) a dirty illness; (3) a horrifying illness; and (4) a young people's illness. The PLWH perceived living with HIV infection as: (1) being tested for faith and patience; (2) time for doing self-evaluation and repentance; and (3) shadowed by feeling of embarrassment.

The PLWH gave meaning to the caring as: (1) accepting the reality of having HIV infection while submitting themselves to God; (2) striving to maintain health by performing optimum efforts and supplication; (3) gaining the blessing of God by doing good deeds and worshipping; and (4) brotherhood and networking to share, support, and help each other. The PLWH performed self-care activities which could be categorized into three types of activities: (1) promoting health and well-being; (2) relieving HIV-related symptoms; and (3) reducing the burden of family care.

The caring and support for PLWH provided by family, health care providers, and the community covered three main areas. These were: (1) physical care included nourishing the PLWH, reminding them to take medication, maintaining cleanliness, and encouraging ways to manage symptoms; (2) emotional care included comforting, being with and helping PLWH; and (3) spiritual and social care included encouraging them to perform worship, accepting the PLWH equally with others, and performing rituals for dying and death PLWH. Muslim cultural beliefs and values that facilitate caring include faith, brotherhood, patience and hardiness, equality, and cleanliness. Caring was impeded by covering disgrace, and misconceptions about destiny. These beliefs are exercised in daily life and shared with each other and influence the meaning of caring and caring activities of PLWH. Overall summary of findings are presented in the Figure 8.



Meanings of caring:
- Accepting the reality of having HIV infection while *"pasrah"*(submitting self) to God
- Striving to maintain health by performing optimum "ikhtiar"(efforts) and *do'a* (supplication)
- Gaining the blessing of God by doing *"kebaikan"* (good deeds) and worshipping
- Building *"persaudaraan"* (brotherhood) and *"jejaring"* (networking)

Perception about HIV and AIDS:
- Deadly illness
- Dirty illness
- Horrifying illness
- Young people illness

Perception about living with HIV infection
- Being tested for faith & patience
- Time for doing self-evaluation and repentance
- Shadowed by feeling of embarrassment

Self-care activities of PLWH		
Promoting health and well-being - Cleaning self - Seeking "good food" for body and soul - Avoiding *"madharat"* (harm) - Connecting self to God by praying more frequently - Gaining supports by involving with self-help group - Concealing HIV status to save face	Relieving HIV related symptoms - Practicing self-healing - Using complementary or alternative therapy - Seeking modern health care assistances as needed - Maintaining ARV adherence	Reducing family care burden - Performing the routine activities to fulfill his/her role - Earning more "rizki" (incomes) with the "halal" ways

Care and supports provided by family, health care provider, community		
Physical care - Nourishing the PLWH - Reminding medication - Cleanliness - Manage symptoms	Spiritual and social care - Encouraging and facilitating *"ibadah"* (worship) - Accepting equally with others - Rituals for dying and death PLWH	Emotional care - Comforting - Being with and helping PLWH

Figure 8 Model of caring for PLWH in Muslim community

Discussion

The findings of this study present the influence of Muslim cultural values and beliefs on caring and living with HIV infection. The informants valued that caring for PLWH was associated with their cultural beliefs and values. Being an HIV-infected person, or having a family member infected by HIV is viewed as a part of a test set by Allah and caring is a form of worshiping Allah. How the PLWH gave meaning to caring and performing self-care to maintain health, and how family, health-care providers and the community provided care and support for PLWH is presented in the Figure 8. The model was derived from Leininger's Sunrise Model (Leininger, 2002a) which suggests that the worldview, environmental context, and the social and cultural values are essential in identifying care expressions, patterns, and practices. The components of the model are discussed below.

Perception about HIV and AIDS, and living with HIV infection

1. Perception about HIV and AIDS

HIV and AIDS have been perceived by the informants in a variety of conceptions. These perceptions reflected the construction of the meaning of HIV and 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 (Chamley, 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 family caregivers 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 and 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 and 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 horrifying or 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 Charnley (2007) who found 74.4% of surveyed Asian Muslim communities (n = 3,517) perceived HIV as a fearful illness.

HIV illness as a young people illness was confirmed by the statistical data published repeatedly in the local mass-media, showing that many PLWH are young people, who were seen as promising for the future development of the country. Data from the Bandung AIDS Control Commission shows that out of 1,636 PLWH reported up to September 2008 in Bandung, 65.51% of them are young adult aged 20 to 29 years (BACC, 2009). HIV/AIDS as a problem of societal development has been addressed by several authors (Hare & Villarruel, 2007; Wolffers, 1997). Wolffers (1997) argued that HIV problems should not be restricted in the area of biomedical, as it covers cultural and developmental aspects of society which touch all levels of society, particularly young people. Hare and Villarruel (2007) emphasized that cultural dynamics of society should be taken into consideration when researching HIV/AIDS related problems among young people.

2. Perception about living with HIV infection

Conceptions about HIV and 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). It is also about the believe in the six 'pillars' include (1) Allah, the One and only God, (2) His Angels, (3) His revealed books, (4) His Messengers, (5) the day of judgment, and (6) predestination. 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 infection 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.

Meanings of caring and self-care activities of persons living HIV infection

1. Meanings of caring for persons with HIV infection

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 (Rassool, 2000; Yosef, 2008). Previous studies documented the influence of faith in believing in God in dealing with

HIV/AIDS impact (Cotton et al., 2006; Maman, Cathcart, Burkhardt, Ombac, & Behets, 2009).

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 (Addarweesh, 2004). Fadlullah (2010) 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. Ahmad Kutty (2002) 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 (Siddiqi, 2003).

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 (Al-Qaradawi, 2002). Feeling of having commonalities which are supported by religious beliefs has driven PLWH and the family caregiver to cultivate a culture of brotherhood which allowed them to share, help, and support each other.

2. Self-care activities by PLWH to maintain health and well-being

Living with HIV infection is vulnerable to other co-infection diseases since the body's immunity was not well functioning. The nature of HIV illness has changed from acute-fatalistic disease to chronic-manageable disease due to the advancement of the antiretroviral therapy. This required PLWH to develop self-care strategies to maintain their health and well-being. Previous studies demonstrate various strategies were developed and practiced by PLWH to maintain health. Eller et al. (2005) found six categories of self-care practiced by PLWH; these were practicing complementary/alternative therapies, talking to others, using distraction techniques, using antidepressants, engaging in physical activities, and using denial/avoidant coping. Gaskins and Lyons (2000) identified three categories of self-care practiced by rural PLWH; they are dealing with rural issues, staying healthy, and the way of taking care of oneself with HIV. Both studies were conducted in the secularized western cultural setting in which the common people are less concerned about religion in their life.

Shambley-Ebron and Boyle (2006) discovered something which contrasted to both mentioned studies, which they called as “redefining self-care”. Their study found that low income African-American women living with HIV preferred to rely on spirituality and religious practices, family support, and their role of mothering to maintain health instead of practicing certain behaviors as prescribed by health care providers. In this present study, the informants demonstrated both approaches: self-care derived from cultural religious beliefs and self-care as prescribed by health-care providers. Three categories of self-care were presented in this study, as there were promoting health and well-being, relieving HIV-related symptoms, and reducing the family-care burden.

“Cleaning self from both visible and invisible dirt” as a way to promote health reflected both professional biomedical belief and religious beliefs. Muslims believe that God is pure and likes purity, and God is clean and likes cleanliness. Therefore, general cleanliness is emphasized in the Qur’an and Hadith. God said: “Truly, Allah loves those who turn to Him constantly and He loves those who keep themselves pure and clean” (Qur’an, 2:222). Cleanliness is not only addressed to body but also to mind and soul, and cleanliness of mind and soul is a prerequisite to total cleanliness (Athar, 1999).

Consuming sufficient nutrition was important to maintain the health of PLWH. The theme “eating more for the body and giving food to the soul” indicates the holistic view of the informants toward the wholeness of body and soul which both require sufficient nutrition. Taking enough food for the body has been a crucial concern among PLWH as was also reported in the earlier studies (Aga, Kylma, & Nikkonen, 2009; Gaskins & Lyons, 2000). “Food for the soul” indicated the belief derived from religion which acknowledges the soul as an integral part of the body. Athar (1999) stated that the human body not only consists of atomic parts and fluid but also the soul, and care for the soul can be fulfilled by performing worship to God such as nurturing faith *(iman),* praying *(shalat),* supplication *(do’a)* and reading the Qur’an, as well as fasting *(sawm)*, charity *(zakat)* and pilgrimage *(Hajj)* to Makkah.

Avoiding harm *(madharat)* for self and others was considered as a self-care strategy to maintain health and well-being. This reflects the Islamic religious teaching which emphasizes on avoiding harm to oneself and others. The prohibition on causing harm is clearly stated in the Qur’an: “Say, My Lord has forbidden all atrocities, whether overt or disguised, and harm (ithm)” (Qur’an, 7:33). Al-Khayat (1997) described that Islam prohibits the Muslims on causing harm also stated by the Prophet Muhammad PBUH; “God will inflict harm to anyone who harm other (Narated by Ibnu Majjah and Abu Dawood following Abu Sirma)”. Keeping away from risky behavior that may cause illness such as using illicit drugs, having illegal sex, homosexuality, and other immoral conducts were considered as examples of avoiding harming oneself. It is also forbidden for Muslim to transmit the disease to others, as that is considered as causing harm to others. The Prophet PBUH said “no infected person should come close to a healthy one (Agreed upon as reported by Abu Huraira as cited in Al-Khayat, 1997)”. For example, this study found four husband informants who said that they always were using condom when having sex with their wife to prevent transmitting a new type of HIV. If they neglected it, they considered it as harming their wife and that made them felt guilty, because it was against their religious belief. It seems that belief of avoiding harm has motivated informants to perform self-care by using condoms as a means of prevention HIV transmission to their spouse.

Prayer *(shalat)* and supplication *(do’a)* was selected as a self-care strategy to maintain connection with God as the source of power. The informants were indicated to utilize Islamic religious practices as a care modality in dealing with HIV-related problems. Utilizing religious practice, particularly prayer, as way of coping with HIV/AIDS has been documented in the previous studies (Corless et al., 2002; Cotton et al., 2006; Shambley-Ebron & Boyle, 2006). In the Muslim perspective, prayer is an obligation and has become an integral part of Muslim life. Therefore, Islam encourages Muslims to be patient and pray consistently while facing illness or when suffering (Athar, 1999; Rassool, 2000).

The existence of self-help groups facilitated by NGOs working for HIV/AIDS has been widely acknowledged as a support system of care for PLWH. This was supported by Foong et al. (2005) who found that NGO played a significant role in providing support and information for PLWH. Uys (2003) asserted that most NGOs worked without government funding, which might lead to a patchy health delivery. This might threat the sustainability of self-help group which has demonstrated to be of significant benefit for PLWH. Since NGOs are mostly funded by foreign donors through time-specific work contracts, some had ceased offering services when the initial funding has been used up (Ibrahim, Songwathana, Boonyasopun, & Francis, 2010).

The remaining prevalence of perceived stigma and feeling shame among PLWH has forced them to conceal or hide their HIV status from public, with the aim to save face or protect reputation. This was congruent with a previous study found that being HIV-positive carries a strong sense of shame for both infected individual and the family (Duffy, 2005; Irwanto & Moeliono, 2007). Since HIV was viewed as an immoral illness, disclosing the HIV status could embarrass the family and the community at large and break the harmonic relationship among families or communities. “Keeping silence” and “saving face” were commonly utilized to maintain the dignity of the family and of the community (Bhattacharya, 2004; Duffy, 2005).

Besides utilizing self-care strategies based on cultural and religious beliefs to promote health, PLWH also utilize various self-care methods to relieve symptoms. The self-healing methods were commonly developed based on experiments and experience or recommended by family or friends. Several earlier studies reported on investigations of self-healing or self-management methods to relieve HIV-related symptoms. Rose et al. (1998) found PLWH who experienced fatigue using strategies such as strictly scheduling activities to preserve their strength, engaging in volunteering activities to ‘push off’ fatigue, ignore it, and slowing oneself down and guarding the remaining energy level. Eller et al. (2005) reported how some PLWH in their study used prayer, meditation or relaxation, and reiki as self-healing methods to manage symptoms.

Using complementary/alternative therapies as a way to relieve symptoms has been chosen by informants too. The reasons of using the therapies were mostly due to uncertainty with modern medicine, being easily available in their area at an affordable price with few side effects. This indicates that PLWH still maintained the belief toward their culturally rooted therapies to heal their illness. This phenomenon not only happened in Eastern countries which people mostly have strong bonding to their cultural heritage and tradition, but also in Western countries. Corless et al. (2002) reported some PLWH used complementary therapies such as acupuncture and meditation, and Eller et al. (2005) noted acupuncture, aromatherapy, and herbs were also used by PLWH in their study.

Seeking modern medicine and health care professional assistances remain to become the main option for most PLWH to heal their illness or relieve the symptoms. Gaskins and Lyons (2000) reported that PLWH rely on physicians in the HIV clinic for their treatment though some of them were bothered by feeling shame due to that some people would then know they attended an HIV clinic. In addition, Irwanto and Moeliono (2007) reported that of some 270 surveyed PLWH; of which about two-third visited health care services to obtain ARV, VCT, and nursing care, several of them encountered barriers such as feelings of fear to be known by relatives or friends, or fear of rejection by health care providers due to their HIV status.

Antiretroviral drugs remain the most powerful regimen to limit HIV proliferation in the body, though many cases of side effects were reported. The experience of dealing with ARV side-effects may lead to discontinue taking ARV medication. Therefore, sticking to ARV, becomes an essential self-care strategy for PLWH for a successful treatment. Gray (2006) discovered how PLWH maintained adherence, and how they reflected several themes such as “choosing life” as a decision initiating treatment, “riding it out” as adjusting to side-effects and overcoming barriers, “figuring it out” reflecting using particular strategies to incorporate pill-taking into daily life, “sticking to it” as overcoming internal resistance, and “realizing the benefits” reflecting successful of the treatment. Sidat, Fairley, and Grierson (2007) interviewed PLWH who were 100% adherent, and found that viewing ARV, as a life-line, willingness to live longer and healthier, establishing an optimally ongoing patient-provider relationship, better coping to side effects, and improvement in clinical condition, are motivating factors for PLWH to remain their adherence to ARV treatment.

PLWH in this study demonstrated their responsibility toward their family by means of reducing the family care-burden resulting from being affected with HIV. Performing the routine activities to fulfill his/her role was identified as a self-care strategy to maintain health. This reflected the culture of valuing the family higher than the individual, which is clearly pronounced in Eastern societies. Gaskins and Lyons (2000) reported a similar finding which they labeled as “staying busy” to represent the strategy used by PLWH to distract themselves from thinking about illness. However, the used strategy focused more on self-fun or being enjoyable, rather than giving benefits for other. Shambley-Ebron and Boyle’s (2006) findings were similar with this study that found African American PLWH women tend to use the strategy of mothering or performing mother’s role as self-care strategy rather than doing enjoyable activities.

"Earning more *"rizki"* (incomes/livelihood) with the *"halal"* (lawful) ways" was another self-care strategy indicating responsibility toward family. This reflected the cultural beliefs about the obligation of work to earn an income in a lawful way. Siddiqi (2009) pointed out about the importance of work and earning an income in the Islamic perspective. In Islam, work is regarded as an act of worship if certain conditions are met. Islam is a religion of action. It calls upon Muslims to work hard to benefit themselves and their societies. The work must be good, *"halal"* or permissible by Islamic *shariah* (law). Work should be done with the consciousness of Allah and with the conviction that everything will be asked for accountability on the Day of Judgment. Therefore, those who work with faith and righteousness, Allah will grant them success in this world and in the Hereafter. It is clear that working to earn some incomes not only is a benefit as a way of caring for themselves, but also incomes gained from such work would be beneficial for the whole family.

Caring and supports for PLWH provided by family, health care providers, and community

1. Physical care

Adequate nourishment for PLWH was viewed as essential to gain and maintain health. This reflected the informants' belief in biophysical function of proper food. Helman (2007) and Leininger (2002b) asserted that food is more than a biological source of nutrition in that it has social, economic, political, religious, and cultural meanings and use. Sharing food in a family and prioritizing available food for a sick family member reflects the cultural value of food, which may thus tighten the bonding of caring among family members. The involvement of relatives, neighbors, and community people in offering food for the sick indicated that food is functioning as a symbol of social ties in the community, and is at the same time a symbol of obedience to the religious teaching. Moreover, the type of food, food preference, and ways of preparing and serving food by a particular person or family may offer a cultural lens by which one can see one’s own social and economic status in the society. A previous study reported that nourishing PLWH was also a conception of caring among family caregivers (Aga et al., 2009).

Reminding PLWH to take medication timely indicated the major concern among family or surrounding people of PLWH about continuity of taking medication. This reflected the belief toward efficacy of a modern medicine like antiretroviral as the best available choice to treat the illness. Earlier studies reported that family caregivers play a significant role in providing basic care for PLWH including taking medication (Maneesriwongul et al., 2004; Vithayachockitikhun, 2006). In addition, higher social support from surrounding PLWH was found to be associated with higher adherence of PLWH to the ARV therapy (Peltzer, Preez, Ramlagan, & Anderson, 2010).

Cleanliness became the main attention of family caregivers and health-care provider in caring for PLWH due to their vulnerability towards other infections. It is also important to recognize the cultural values and beliefs underlying the practice of cleanliness. As mentioned earlier, cleanliness is perceived not only within the boundaries of the biomedical framework based on the germ theory, but also involves religious beliefs as a subject of religious teaching (Athar, 1999; Yosef, 2008). These findings also support a previous study that found maintaining cleanliness and hygiene for persons with AIDS as a meaning of caring among family caregivers who care for HIV-infected family member (Aga et al., 2009).

Supports to manage symptoms were offered by the family caregiver and health provider in line with their knowledge and capacity. Helman (2007) pointed out that when one recognized any ill-symptoms of his/her body, he/she may initiate to get through into the hierarchical health-care ranged from popular, folk, and to professional health care. Popular health care is usually the first choice because it could be applied without payment or consultation with a folk healer or health care professional. It includes such self-healing methods as there are self-medication, advice or treatments given by family, relatives, and friends. In this context, the main arena of health care is the family, and the main provider is any woman, usually the mother or the wife. This supports previous studies that found women were culturally expected to be care giver for the HIV-infected family member (Songwathana, 2001; Vithayachockitikhun, 2006). This symbolizes the cultural pattern of care that should be recognized by health care providers.

2. Emotional care

Comforting PLWH by offering advice and entertaining may also be provided by the family, the health provider, and the community as a mode of care for the PLWH. From the cultural context of the participants, providing comfort symbolizes expression of love and affection that exists within familial, professional, and community relationships. It is also supported by religious beliefs that teach them how to behave toward the sick person. Yaqut (2007) asserted that honoring the disabled as well as the sick persons, meeting their needs and comforting them is encouraged by Islam for the purpose of relieving their suffering. The Prophet

Muhammad (PBUH) used to visit the sick, pray for them, and consoled them, instilling confidence in their souls, and covering their hearts and faces with happiness and joy. Family caregiver provided comfort and emotional support for PLWH, as documented in a recent study (Aga et al., 2009; Maneesriwongul et al., 2004).

Presenting self physically or being with and helping PLWH, were acknowledged as a practice of emotional care for PLWH. From the nursing perspective, “presence” has been well-known as an attribute of caring (Brilowski & Wendler, 2005). Presence used to represent the nurse uses self as a tool to be totally present. It consists of listening carefully, allowing time to sharing, communicating, and showing interest and engagement. Covington (2005) examined the meaning of ‘caring presence’ from both the nurses’ and patient’s perspectives. She concluded that caring presence is a relationship between two people who share themselves through ways of being, behaving, and feeling. It consists of mutual trust and sharing, transcendent connectedness, and metaphysical experience. Previous studies reported family caregivers using physical presence to console PLWH (MacNeil, 1996; Songwathana & Manderson, 2001).

3. Spiritual and social care

Encouraging and facilitating PLWH to perform *“ibadah”* (worship) was raised by the family caregiver, health care providers, and community participants as a form of caring practice for PLWH. It is essential to recognize that worship is the essence of being human in this world according to the Muslim perspective. Worship in Islam is inclusive of everything which is pleasing God, whether they deal with issues of belief, or deeds of the body. It may include everything a person perceives, thinks, intends, feels, says and does. It also refers to everything that God requires, externally, internally or interactively. This includes rituals as well as beliefs, work, social activities and personal behavior, as every human being is a whole, such that every part affects every other ("Worship in Islam: The meaning of worship," 2007). Al-Qaradawi (2003) described the first aim of worship is to demonstrate how far a Muslim obeys Allah's commands and shuns what He, the Almighty, forbids. This is the main aim of all forms of worship including prayer, fasting, obligatory charity, reciting the Qur'an, and following Allah's commands regarding what is permitted and what is prohibited. The second aim is to reform the soul and to obtain virtue. For example, prayer is originally meant for worshipping Allah, resorting to Him in sincerity, feeling humble before Him, and reminding remembrance of Allah.

Many previous studies reported the prevalence of stigma and discrimination toward PLWH in the community level in the Asian region (Merati et al., 2005; Paxton et al., 2005; Reidpath et al., 2005). Even in another region, attitudes of community members were discouraging and harmful that made PLWH feared being identified as HIV-positive (FHI Ethiopia, 2002). PLWH need social acceptance and empathy to help them deal with the traumatic nature of their situation. In contrast, this study found that community people indicated their acceptance toward PLWH. This was reflected by their perception which expressed “accepting PLWH as a community member equal with others as a form social care provided by community”. Although this finding could not be generalized to the whole population, it is indicated in some degree, community people were willing to accept any PLWH as a community member who has equal rights as have other members. Conception of “equality” seems to reflect the notion of their Islamic belief which is a basic element in the value system of Islam. Rizvi (2010) asserted that in Islam all human beings are basically equal in the sight of Allah. Islam rejects all artificial and man-made marks of distinction and no one can claim any superiority over the other based on race, color, language, social status, or wealth. Allah clearly declares in the Qur'an: "O mankind, verily, We have created you from a single (Pair) of a male and a female, and have made you into nations and tribes, that you may know each other. Verily the most honored of you in the sight of God is the most righteous (Qur'an, 49:13)". According to this verse, all humans can trace their origin to Adam and Eve. Allah has divided them into different tribes and races so that it may be easy to recognize each other. Thus the difference in race, tribe, color and language are to facilitate the recognition of each other. These physical and material differences cannot be a standard for preference or superiority of one over the other.

Performing the ritual for dying and death of PLWH was recognized as a type of caring practice given by the family and the community. This ritual can be illuminated by the Islamic perspectives toward death and dying. In Islam, life is a journey through the world, and death is another journey through a spiritual world to meet God (Athar, 1999; Rassool, 2000). The earth is described as a resting place for the purpose of worshiping God and doing good deeds. Muslims value much on sanctity of life meaning that all life is sacred and a trust from God, because it originates with God and returns to God (Sheikh, 1998). Hedayat (2006) stated; Muslims traditionally defined death as when the body grew cold after cessation of cardiac activity, despite it was based on more empirical observations than on prophetic command. Attending to a sick person and/or the funeral procession is highly recommended in Islam. Burial of the dead is a communal responsibility of the Muslim community.

In the dying moments, Muslim visitors recite or listen to the recitation of certain key verses of Qur'an, commonly *"Surah Yasiin"*. The rituals surrounding the time of death are commonly consisted of making a will and testament, seeking forgiveness, reciting the Qur'an, reiterating key beliefs (profession of faith by saying *"La ilaha illa Allah wa-Muhammad rasul Allah"* (there is no god but Allah (God) and Muhammad is the prophet of God), facing *Makkah* at the time of the death or head turn to the right if not practical, closing the eyelids, closing and/or binding the jaw, and the body must be ritually washed, anointed, shrouded, prayed over, and be buried within 24 hours. Mourning in a loud voice and crying in a high pitch was prohibited by the Prophet Muhammad (PBUH) (Sajid, 2003). It is a Muslim's duty to offer condolences, comfort and sympathy to the family and the relatives of the deceased. This strengthens the relationships within the Muslim community.

Cultural beliefs and values associated with caring for PLWH

1. Cultural beliefs and values facilitating caring

Faith *(iman)* was identified as the belief of facilitating caring by the participants in this study. In Islam, faith is the fundament of the religion. Faith is not merely the conviction of the truth of a given principle, but it is essentially the acceptance of a principle as a basis for action. In Islam, faith is about the belief in the Unity of God or *Tawheed.* This is expressed in the primary *kalimah* (Word) of Islam as: *"Laa ilaaha illallaah"*, meaning: "There is no one worthy of worship but Allah." The acceptance or denial of this phrase produces a world of difference among human beings. The relation between faith and caring perhaps can be explained as follows: faith in Islam reflects a person's dedication to God's will and the recognition of His sovereignty (Schirrmacher, 1997). This has consequences for his behavior in the family, in society and in the State need to obey God's rule. Simply, if God commands all humans to love and care for each other, the believers must behave in that way if they wish to gain the blessing of God.

Brotherhood was considered as the value facilitating caring in this study. This was underlay by the Islamic teaching which orders one should love one's brothers as one loves himself. It was confirmed by the Prophet (PBUH) saying: "Each of you cannot be a believer until he loves his brother as he loves himself" (Reported by Abu Hamzah Anas bin Malik as narrated by Al-Bukhari & Muslim as cited in "None of you truly belive until...", 2008). The foundation of this brotherhood is not a mere relationship joined by blood or race, but formed with the rope of *aqidah* (faith) as God stated in the Qur'an Surah Hujurat: 10: "The believers are but a single brotherhood: So make peace and reconciliation between your two (contending) brothers; and fear Allah, that ye may receive Mercy"(MUIS, 2002). It can be seen that faith is the foundation in building brotherhood and love as a main element of brotherhood. Since love is one important characteristic to establish caring relationship (Brilowski & Wendler, 2005), it is clear that the concept of brotherhood may facilitate caring.

Patient *(sabar)* and hardiness/endurance *(tabah)* is a quality of ability in experiencing difficulties without complaining or showing emotions. It was considered by the participants as a value facilitating caring. Patience and endurance reflects the steadiness in facing difficulties in life. Al-Munajjid (2010) illustrated the essence of patience and endurance as he said "Allah has made patience like a horse that never gets tired, an army that can never be defeated and a strong fortress that can never be breached". If the concept is applied in the caring situation, it could be an antecedence condition which reflects the quality of a person who performs caring behavior (Brilowski & Wendler, 2005). This was also asserted by Watson (1990) said that caring in nursing requires informed moral action and passion. Therefore, patience and endurance can promote quality of caring both caring for oneself and for others.

Equality *(kesetaraan)* is the value that may positively contribute to caring. Equality is a basic element in the value system of Islam (Rizvi, 2010). Congregational prayer *(Shalat berjamaah)* and pilgrimage *(Hajj)* is the most obvious example of the Muslim ritual worship that promotes equality. For example, in a congregational prayer, all stand in lines regardless of any difference of race, tribe, color, language or wealth, then when in the position of *sajdah* (prostration), there is no reservation in the rows of congregational prayers, and everyone will be reciting in the same language, and doing exactly the same action at the same time. In caring science perspective, equality has been noted as a prerequisite for an ideal egalitarian caring relationship between nurse (caring provider) and client (caring recipient) (Sumner, 2001). In this relationship, each party brings its historical and cultural background in a specific health/illness situation to achieve a goal of meeting particular needs. The equality in the relationship may facilitate the harmonious exchange between the power of compassion of the nurse and the patient’s own efforts to reach the goal. This result may contribute to growth and satisfaction for both nurses and patients.

Cleanliness *(kebersihan)* was recognized as the value that promotes caring. Health care professionals including nurses, have been growing in the belief of biomedical framework which strongly believe in the theory of germ. Germ theory states that many diseases are caused by the presence and actions of specific micro-organisms within the body ("Germ theory,"). This classical theory is still widely applied and serves as a foundation for the control of microbial transmission which causes disease. Cleanliness and hygienic practices are closely linked to the theory as a means to cut the chain of micro-organism transmissions. It is simply understandable that cleanliness can promote caring since caring also concern the prevention of illness transmission and of recovery from a disease.

2. Cultural beliefs and values impeding caring

Covering disgrace *(menutup aib)* was viewed by the participants as the belief impeding caring. Disgrace refers to the embarrassment or feeling ashamed resulting from behavior that makes other people loose respect. Kobeisy (2004) defined shame as painful emotions aroused by the recognition that one has failed to act, behave or think in accordance with the standards which one accepts as good. The same feeling is aroused by similar failures in others with whom one identifies oneself. Shame is equated with dishonor, disgrace and something that brings regret, censure or reproach. Shame is often associated with conscientious of guilt, weakness, or impropriety. In the Islam perspective, bashfulness or feeling shame is a required characteristic of the human function which is considered valuable if used in moderation and as a preventive mechanism against the engagement of shameful actions and events. Shame that results from exposure to embarrassing or shameful situations can result in either physical or social actions or both. The physical actions include looking down and blushing while the social ones include hiding from people and withdrawal. Among many factors causing shame is the type of illness: social and visual illnesses may bring a great deal of embarrassment and shame to the patient, particularly those linked to life-style practices and morality such as sexually transmitted diseases, HIV, and sexual dysfunctions. If the feeling of shame is too much, patients may hide themselves or withdraw from society. As a result, they were less likely to access the health care services and their health problems are hard to be identified in society. Therefore, this may impede to caring practice for those people.

Misconception about destiny *(nasib)* was identified as the belief impeding caring. In the Islamic perspective, A Muslim must believe in the destiny *(qadar in Arabic)*. The concept of destiny used in the Qur'an means a measure or the latent possibilities with which Allah (God) created human beings and all things of nature. When Allah created each thing, He determined when it would come into existence and when it would cease to exist. He also determined its qualities and nature. Everything in the universe, the seen and the unseen, is completely subject to the overriding power of Allah. Nothing can happen outside His Will ("Divine decree,"). Kasule (2004) asserted, it is God's predestination that a person falls sick. Treatment, prevention, and care of disease are not against destiny. Medical treatment is subsumed under the principle that *qadar* can reverse another qadar *(radd al qadar bi al qadar)*. Khan (2004) stated, illness is an examination of life and suffering from the illness itself means purification of the sins. Therefore, the sick person need to be patient and should not lead to passivity or fatalism. Hameed (2002) described that being fatalistic toward suffering from illness is discouraged by Islam. Allah Almighty in the holy Qur'an says, "Allah changes not the condition of a folk until they (first) change that which is in their hearts (Qur'an, 13:11)". This verse clearly tells that: it is Allah Who changes the condition of a people; second, it is the people who should first effect a change in their own souls if they wish to have their condition changed for the better. Thus, humans are not entirely powerless and helpless in this world; rather, they have a clear role in shaping their lives. So, the salvation of humans is not dependent on causes beyond their control, but on their own willful choice and effort. That is His Will too. In the context of caring, it is clear that misconception about destiny may lead to passivity or fatalism in putting efforts to overcome health problems. In turn, it may impede the achievement of caring outcome especially healing and wellness.

Overall, those values and beliefs both facilitating and impeding caring are embedded in daily life of the informants. The beliefs are not isolated in a single concept, but they may share each other. For example, in Islam, faith is a basis for a human’s actions ("The Islamic concept of faith," 2006). Moreover, the values of patience, brotherhood, equality, hardiness, cleanliness, destiny, and disgrace, are grounded in the faith which leads human to obey and submit to the Will of Allah. For example, Al-Munajjid (2010) points out patience as the foundation of the believer’s faith. Those who show “patience” in facing suffering reflected having strong faith. Although research evidences regarding association among those beliefs are still extremely limited, general understanding can be drawn that cultural values and beliefs have shaped caring both in meaning as well as activities.

In summary, findings of the study reflect universality and diversity of values and beliefs underlying care phenomenon, especially care for PLWH. Belief in modern health care practices reflects universality of care which nowadays dominated by the approach of scientific evidenced based western medicine. Diversity of care could be pointed out by highlighting utilization of religious belief and spirituality in facilitating caring. For example, the belief of faith in God, value of patience and hardiness in facing suffering reflect the unique manner of the believer in performing caring for self as well as caring for other persons.

CHAPTER 5

CONCLUSIONS AND RECOMENFATIONS

This chapter presents the conclusions of the study. Recommendations for the nursing practice, for nursing education, and for further research are addressed.

Conclusions

Given the fact that HIV/AIDS remains a major public health concern in the Bandung District, and that caring for PLWH with respect to the cultural context of population has not yet well-developed, this qualitative focused ethnography study, entitle "Muslim cultural care for people living with HIV infection in the Bandung Community, Indonesia", aims to elucidate cultural beliefs, values, and practices related to caring for people living with HIV infection in Muslim community. This includes perceptions about HIV and AIDS and living with HIV infection, meanings of caring and self-care activities, and care and supports provided by the family, health care providers, and the community. Cultural beliefs and values associated with caring were also presented.

This study was theoretically underpinned by the Leinginger's theory of culture care diversity and universality. The theory hypothesizes the existence of care diversity and universality among cultures, which need to be discovered and analyze for their meanings and usage. The ethnonursing method was used to achieve this goal of the study. Twelve key informants and twenty six general informants participated in this study. Data were collected by the researcher using several methods including participant observation, interviews, focus group discussions, and examination of available documents. Field notes were generated from the participant observations. The interviews were tape recorded and transcribed subsequently, paralleled with data analysis. Leinginger's phases of ethnonursing analysis for qualitative data were used as a guideline to analyze all information gathered since the beginning of fieldwork. The findings indicate that Islamic belief and values have shaped the perceptions, meanings, and practices of caring for PLWH.

HIV and AIDS have been perceived in various conceptions by the informants. Before exposing to the update information, HIV/AIDS was perceived as an illness of prostitutes or being due to illicit sex. This perception gradually changed along with the exposure to the updated information related HIV and AIDS and the HIV epidemic in Bandung. Both HIV and AIDS were predominantly perceived as a deadly illness, a dirty illness, a horrified illness, and a young-people's illness. These perceptions were constructed based on the integration and interaction of understanding HIV/AIDS from the biomedical view point and from the cultural belief's perspective. Regarding to living with HIV infection, it was perceived as being tested of *iman* (faith) and *sabar* (patience) through ups and downs of HIV-related sufferings; as time for doing *"mawas diri"* (self-evaluation) and *"insyaf"* (repentance); and shadowed by the feeling of *"malu"* (embarrassment). These perceptions reflected the strong influence of religious beliefs in driving an understanding towards living with HIV infection.

Key informants described meaning of caring for self as accepting the reality of having HIV infection while submitting self to God, striving to maintain health by performing optimum *"ikhtiar"* (effort) and *"do'a"* (supplication), gaining blessing of

God by doing good deeds and worship, and building brotherhood and networking to share, support, and help each other. These meanings indicated illumination of religious belief in extracting important values to represent concepts of caring from the PLWH's world view. To maintain health and well-being, PLWH developed various self-care strategies, based on both cultural beliefs and modern health care practice.

Care and supports for PLWH provided by family, health care providers, and community were categorized into three groups of care domains: physical care, emotional care, and spiritual and social care. Physical care consists of nourishing the PLWH, reminding PLWH to take medication timely, maintain cleanliness of PLWH and of their environment, and encouraging ways to manage symptoms. Emotional care includes comforting PLWH by offering *"nasihat"* and *"melipur"*, and being with and helping PLWH. Spiritual and social care includes encouraging and facilitating performing *"ibadah"* (worship), accepting a person with HIV infection as a community member equal to others, and performing rituals for dying and death of the PLWH. These caring practices exhibited the underlying beliefs which influence such practices. Beliefs in the biomedical framework of the disease and its cause are more likely to underpin the practice of physical care though cultural religious beliefs also were utilized. Cultural and religious beliefs have indeed a strong influence on emotional, spiritual, and social care.

Several factors derived from cultural beliefs and values have been identified as having an association with caring as either as a facilitating factor, or as an impeding factor. The caring promoting factors include faith, brotherhood, patient and hardiness/endurance, equality, and cleanliness, whereas caring impeding factors include covering up *"aib"* (disgrace) and misconceptions about destiny. Faith is the central and fundamental issue in Islamic belief, which strongly influences Muslims' perceptions and practices with regard to health, illness, and care. Brotherhood, patience, hardiness, equality, and cleanliness clearly represent some essential values in the Islamic value system, all of which may have a positive effect on caring behavior. However, the values of disgrace and destiny may still come with misconceptions which may hamper the caring behavior. These values and beliefs are possibly interrelated to each other and provide a rich context of caring from the Islamic perspective.

Overall, Islam has shaped the perception of the informants toward HIV and AIDS, living with HIV infection, and care for PLWH. Islam advocates Muslims to look after and to assist each other with love, compassion, and sincerely as a manifestation of worshiping God to gain blessing of God. The family has the obligation to take care a family member who is sick, regardless of the type of his/her illness or cause of the illness. The kinship, the dominant family role in caring, and the belief in modern health care reflect the universality of the care phenomenon. Thus, utilizing Islamic belief and values such as faith, patience, hardiness, brotherhood, cleanliness, combined with religious practices such as prayer, reciting Qur'an, meditation *(dzikir)*, and supplication are likely reflecting the diversify and uniqueness of caring phenomena in the Muslim community. However, HIV/AIDS remains to be viewed as a horrifying illness which historically links with “immoral” behavior. In response to this issue, PLWH prefer to hide their HIV status from the community by pretending to live as a normal life.

Recommendations

The findings from this deep and rich details qualitative study show that Islamic beliefs and values have shaped the structure of experience of meanings and activities of caring for people living with HIV infection in the Muslim community. This has been reflected in the perceptions of HIV and AIDS and living with HIV infection, meanings of caring and self-care activities of PLWH, care and supports for PLWH provided by family-health care provider-and community, and cultural values and beliefs associated with caring. All these have resulted in the significant suggestions and recommendations for nursing practice, for nursing education, and further research as the following:

Nursing practice

The findings indicate that the image of HIV and AIDS as horrified or fearful illnesses is still obvious, particularly among general people who are less exposed to the continuously updated information about HIV and AIDS. This implies nurses in both community health centers and hospital settings should be aware of changing concepts when dealing with HIV patients and their family and companions, and need to assess their level of HIV-related knowledge prior to providing nursing interventions. Community nurses can use this finding as a point for consideration when working with community elements such as community leaders, volunteers, NGOs, and religious leaders. Media coverage about HIV and AIDS has been identified as a reinforcing factor to image HIV as a fearful illness. Thus, nurses can use the findings of this study to advocate the journalists and mass media practitioners to reconsider and redesign the ways of portraying news about HIV, in order to minimize the negative image of HIV and AIDS among the general population.

The findings clearly show “Islamic faith” are utilized as a way of coping to preserve life and living with HIV infection. Nurses can develop nursing interventions to instill “faith” for HIV patients and family either as independent role of nursing, or collaborate with spiritual/religious experts. It is advisable to use the values of Islamic belief as found in this study such as patience *(sabar)*, submitting self to Allah *(pasrah)*, putting optimal effort *(ikhtiar)*, supplication *(do’a)*, doing good deeds *(kebaikan)*, and brotherhood *(persaudaraan)* to encourage PLWH in caring for themselves. Some values such as disgrace *(aib)* and destiny *(nasib)* still cause misinterpretations that lead PLWH to hide themselves and being fatalistic. Nurses should anticipate these beliefs and be more aware about the consequences of having these beliefs. Involving success models of PLWH in discussion with those who have these beliefs could be useful to open their insight and confidence. Nurses should also encourage PLWH who have used various self-care strategies, as acting as a good counselor or educator when they need assistance in developing the strategies.

The findings from general informants who care for PLWH reflected their commitment in fulfilling their responsibility either as a caregiver or a community leader, and the most important as a worshiper of Allah. This implies nurses should always realize when dealing with Muslims that whatever Muslims do should be basically viewed as their worship to Allah. Thus, facilitating the worships would be necessary. Overall, nurses should acknowledge the cultural religious beliefs and values attach to the clients and related persons and use those values and beliefs to design culturally sensitive nursing care.

Nursing education

The nursing education in Indonesia, as in many other countries, is mainly developed in Western scientific framework which pays less attention to incorporate local knowledge and wisdom with respect to health and well-being. The Muslim population constitutes the largest majority in the country and they may have their own worldview toward illness, health, and well-being. Nurse educators should lead nursing students to competence in providing culturally sensitive care, particularly for Muslim patients.

Further research

The findings of this study can serve as an essential foundation for participatory action research aiming to develop a culturally sensitive model of the community home-based care for PLWH in our Muslim community. Islam is not merely a religion but also a way of life which is rich in values and traditions. Further exploration about the Islamic values and traditions related to positive living and caring for PLWH in other low prevalence settings as well as in other ethnic populations is needed.

Limitation of the Study

The researcher found some limitations while working in the field during data collection. Certain informants of nurses who initially planned to be interviewed were not included. The staff rotation policy issued by the District Health Office has caused some nurses who had been trained in the area of HIV care in the community health center to move to other health centers that have no special service for HIV/AIDS. The health center that usually offers health care services for PLWH was operated by the new appointed staffs that mostly have no training background related HIV care. This has hampered the researcher in gathering more qualified nurses to capture their experience in caring for PLWH in the community.

In the process of analyzing data and writing the report, language barrier is also problematic. Although the researcher has been assisted by professional English Teacher, some words in Sundanese or Indonesia language still could not be appropriately translated to English. To deal with this issue, the researcher tried to search the words that have closest meaning to the original ones and tried to find English native to discuss and overcome the issue.

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APPENDIXES

APPENDIX A

PERSONAL INFORMATION FORM

(Key informant)

Informant Code: ………………………

1 Age ……………years old

2 Gender: ( ) 1. Female ( ) 2. Male

3 Ethnicity:…………………………………………………….

4 Address:

………………………………………………………………………………………

…………………………………………Phone number……………………….……

5 The highest completed educational level

( ) 1. Primary School ( ) 2. Junior High School

( ) 3. Senior High School ( ) 4. University/College

( ) 5. Others (specify)……………………………………………………………...

6 Recent occupation or main activity

( ) 1. Student ( ) 5. Volunteer

( ) 2. Government employee ( ) 6. House wife

( ) 3. Private employee ( ) 7. Others (specify) …………………

( ) 4. Business

7 Average monthly income: …………………………………………………………

8 Number of family member who live in the same household………………persons.

9 Present position in the family:...

10 Length of time of knowing HIV positive status:……………………………………

11 Recent CD4 count: …………/mm3, Date:……………………………………..

12 Current treatments: ………………………………………………………………

………………………………………………………………………………………

………………………………………………………………………………………

………………………………………………………………………………………

APPENDIX B

PERSONAL INFORMATION FORM

(General informant: Family & Community)

Informant Code: ………………………

1. Age ……………years old
2. Gender: (   ) 1. Female   (   ) 2. Male
3. Ethnicity:…………………………………………………….
4. Address:

   ………………………………………………………………………………………

   …………………………………Phone number…………………….……………
5. The highest completed educational level

   (   ) 1. Primary School   (   ) 2. Junior High School

   (   ) 3. Senior High School   (   ) 4. University/College

   (   ) 5. Others (specify)………………………………………………
6. Recent occupation or main activity

   (   ) 1. Student   (   ) 5. Volunteer

   (   ) 2. Government employee   (   ) 6. House wife

   (   ) 3. Private employee   (   ) 7. Others (specify) …………………

   (   ) 4. Business
7. Relationship with the key informant……………………………………………..
8. Length of time of knowing the key informant..:……………………………………

APPENDIX C

PERSONAL INFORMATION FORM

(General informant: Nurse)

Informant Code: ………………………

1. Age ……………years old
2. Gender: ( ) 1. Female ( ) 2. Male
3. Ethnicity:…………………………………………………….
4. Address:

   ………………………………………………………………………………………

   …………………………………………Phone number…………………….………
5. The highest nursing education has been completed

   ( ) 1. Senior High School ( ) 2. Diploma III

   ( ) 3. Bachelor ( ) 4. Others (specify)………………….
6. Working affiliation

   ( ) 1. Government teaching hospital

   ( ) 2. Government public hospital

   ( ) 3. Public health center

   ( ) 4. Private sector

   ( ) 5. Others (specify) ………………………….

9. Working experiences in caring for HIV/AIDS patients…………..months
10. Trainings/short courses related to the field of HIV/AIDS care have been completed

Name of course	Duration/Year	Hosted Institution

APPENDIX D

INTERVIEW GUIDE

Interview questions have been developed to guide interview. However, the interviewer may modify or add some important questions along the process of interview if needed. The following area was explored with the **key informants**:

General topics

(1) How is your life going on today?

(2) How do you perceive your current health?

Perception about HIV/AIDS and living with HIV/AIDS

(3) Tell me about HIV and AIDS? How did you know the diagnosis? What does it mean to you?

(4) What is like to be a person with HIV positive? How did your life different from other people? What does make you think like that?

Caring for PLWH

(5) Tell me how do you care for yourself in order to be healthy?

(6) What does care mean to you?

(7) When do you receive care from family? In what way or what conditions do you receive the care?

(8) When do you receive care from community? In what way or what conditions do you receive the care?

(9) When do you receive care from health care provider? How and in what conditions do you receive the care?

Cultural beliefs aspect of caring

(10) What are your beliefs regarding illness, health, and care related to being an HIV-infected person?

(11) Where are the beliefs from?

(12) How do the Islamic values and beliefs influence your caring with HIV/AIDS?

The following area was explored with the **general informants**:

Family care giver

(1) How do you and other people perceive HIV/AIDS and people with HIV/AIDS?
(2) How do you take care for your family member who gets HIV infected?
(3) How does his/her HIV status make you decide to take care for him/her?
(4) What are the factors that you think may influence caring for people with HIV/AIDS in family?
(5) How do the Islamic cultural beliefs influence yourself and caring for family member who gets HIV infected?

Health care provider

(1) How do you or other people perceive HIV/AIDS and people with HIV/AIDS?
(2) How do you take care for people with HIV/AIDS?
(3) What are the factors that you think may influence caring for people with HIV/AIDS?
(4) Could you describe any caring practices for people living with HIV/AIDS that reflect your beliefs and culture?

Community leader

(1) How do you and community people perceive HIV/AIDS and people with HIV/AIDS?
(2) What does the community do for people who get HIV infected?
(3) What are the factors that you think may influence caring for people with HIV/AIDS in community?
(4) How do the Islamic cultural beliefs influence community people in respond to people with HIV/AIDS?

APPENDIX E.1

OBSERVATION GUIDE (GENERAL)

Space, describe physical layout of the place where the observation conducted:

....

Actors, describe people who involved in an event under investigation:

…………………………………………………………………………………………………..

Activities, describe the actions by people who involved in an event under investigation:

………………………………………………………………………………………………….

Objects, record artifacts such as implements used for care, documents, pamphlets, etc.:

………………………………………………………………………………………………….

An event, a set of related activities carried out by people who involved in an event under investigation:

…………………………………………………………………………………………………

Time, when the observation was made, when the activities occurred during those times, any effect of time on social situation:

…………………………………………………………………………………………………..

Goal, what group specifically hopes to achieve in the situation:

…………………………………………………………………………………………………..

Feelings of each social situation, emotions expressed and observed:

…………………………………………………………………………………………………..

Additional notes:……………………………………………………………………..…

Besides these guides, the content of previous interview and observation will be used to guide the next observation.

APPENDIX E.2

Leininger's observation-participation-reflection guide

Phases	**1**	**2**	**3**	**4**
Focus	Primarily observation and active listening (no active participation)	Primarily observation with limited participation	Primarily participation with continued observations	Primarily reflection and reconfirmation of findings with informants

APPENDIX F

FIELD NOTE TAKING FORM

Name : ………………………………………………………………………….

Date/time : ………………………………………………………………………….

Place : ………………………………………………………………………….

Activities/Event	Theoretical notes	Methodological notes	Personal notes

APPENDIX G

Leininger's Stranger to Trusted Friend Enabler

Indicators of stranger (Largely etic or outsider's view)	**Date Noted**	**Indicators of trusted friend (Largely emic or insider's view)**	**Date Noted**
Active to protect self and others. They are *'gate keepers'* and guard against outside intrusions. Suspicious and questioning.		Less active to protect self. More trusting of researchers (their *gate keeping is down or less*). Less suspicious and less questioning of researcher.	
Actively watch and are attentive to what researcher does and says. Limited signs of trusting the researcher or stranger.		Less watching the researcher's words and actions. More signs of trusting and accepting a new friend.	
Skeptical about the researcher's motivates and work. May question how findings will be used by the researcher or stranger.		Less questioning of the researcher's motives, work and behavior. Signs of working and helping the researcher as a friend.	
Reluctant to share cultural secrets and views as private knowledge. Protective of local lifeways, values, and beliefs. Dislikes probing by the researcher or strangers.		Willing to share cultural secrets and private world information and experiences. Offers mostly local views, values, and interpretations spontaneously or without probes.	
Uncomfortable to become friend or to confide in stranger. May come late, be absent, and withdraw at times from researcher.		Signs of being comfortable and enjoying friendship-a sharing relationship. Gives presence, is on time, and gives evidence of being *a genuine "true" friend*.	
Tend to offer inaccurate data. Modifies *truths* to protect self, family, community, and cultural lifeways. Emic values, beliefs, and practices are not shared spontaneously.		Wants research *truths* to be accurate regarding beliefs, people, values, and lifeways. Explains and interprets emic ideas so researcher has accurate data of the culture and informant.	

APPENDIX H

SUMMARY OF CHARACTERISTICS OF THE KEY INFORMANTS (N=12)

Informant	Gender	Age (Years)	Marital Status	Number of children	Occupation	Education *	Length of time of knowing HIV status	ART Status	Last CD4 count (/mm^3)	Symptoms/ health status experienced when being interviewed
K1 (Ex IDU)	Male	33	Married	1	Self-employed	JHS	> 1.5 years	On ART	600	fatigue, underweight, numbness on legs, skin irritation (herpes), breast enlargement
K2	Female	38	Widow	2	Housewife	SHS	> 1.5 years	On ART	67	healthy
K3 (Ex IDU)	Female	31	Widow	3	Housewife	SHS	> 4 years	Not yet	700	headache when get distressed
K4	Female	22	Married	1	Housewife	SHS	> 3 years	Refuse	118	severe diarrhea, underweight, weakness, dyspnea, black marks on the skin, blindness
K5 (Ex IDU)	Male	27	Single	0	Unemployed	SHS	> 3 years	Drop out	415	diarrhea, underweight
K6 (Ex IDU)	Male	36	Married	0	Self-employed	SHS	> 1.5 years	On ART	173	fatigue, numbness & pain on feet palms, underweight, wound on limp nodes of the neck
K7	Female	18	Married/ Separate	1	Housewife	PS	> 6 months	Drop out	86	fatigue, diarrhea, underweight, nausea, vomiting
K8	Female	32	Married	2	Housewife	Bachelor	> 2 years	On ART	150	healthy
K9	Male	23	Married/ Separate	1	Self-employed	JHS	> 6 months	Drop out	85	dyspnea, cough, stomach pain, lack of appetite, underweight
K10 (Ex IDU)	Male	27	Married/ Separate	1	Self-employed	SHS	> 5 years	On ART	500	underweight
K11	Female	39	Married	1	Housewife	SHS	> 4 years	On ART	280	underweight
K12 (IDU)	Male	33	Married	0	Private sector	SHS	> 2 years	On ART	577	fatigue, lack of appetite, underweight

**PS = Primary School, JHS = Junior High School, SHS = Senior High School*

APPENDIX I

INFORMED CONSENT FORM

Dear informants,

My name is Kusman Ibrahim. I am a Ph.D student of Faculty of Nursing, Prince of Songkla University, Thailand. I am conducting a research project for doctoral degree study. The purpose of this study is to explore Muslim cultural care for people living with HIV infection in Bandung, Indonesia. Information gathered from you will provide valuable information as a baseline data to develop a culturally sensitive model of care for people living with HIV/AIDS. Therefore, I would like to ask your favor to participate in this study. If you do agree to participate in this study, you will be interviewed and it will take time around 45 to 60 minutes. If you have question about the study, I will be glad to explain it to you. All of your answer and your identity will not be revealed. All information will only be used for purpose of this research project.
There is no risk to participate in this study. Your participation is voluntary in nature, you may withdraw from this study at any time even after start the interview process. There will no penalty or any effect of your decision to refuse to participate in this study. Your signature in this form will indicate that you understand this form and you willing to participate in this study.

Signature : ………………………………….
Name : ………………………………….
Date : ………………………………….

Kusman Ibrahim
Faculty of Nursing, Padjadjaran University
Jl. Bandung Sumedang Km 21 Jatinangor Sumedang Indonesia
Phone: +62227795xxxx Mobile 08132128xxxx e-mail: kusman_ibrahim@yahoo.com

APPENDIX J

FO$_2$ Student form

Faculty of Nursing, Prince of Songkla University

Criteria for Approval of Institutional Review Board

Name: Mr. Kusman Ibrahim **Code:** 5010430009 **Year** 1 **Date** 17 April 2008
Thesis Title: Muslim cultural care for people living with HIV/AIDS in Bandung, Indonesia
Please determine all of the following items for research approval regarding ethical components (issues)

	Yes	No
1. There are risks to subjects	☑	☐
If any, please identify..		
2. Research plan provides adequate monitoring for risks	☑	☐
3. The appropriateness of subject selection (Sampling , equity of selection)	☑	☐
4. Respect to subject's risks to clearly identified	☑	☐
5. Informed consent is presented	☑	☐
6. Confidentiality of data is maintained throughout the research process	☑	☐

Results

☑ Exempt

☐ Need to be approved by IRB

☐ Notify the researches to correct as follow :

....

....

....

Evaluator's Signature...

(Ladawan Prateepchaikul)

Date 04/17/08

To Chair of IRB

The researcher has already corrected as follow:

1...

2...

3...

(..)

Researcher

FAKULTAS KEDOKTERAN UNPAD - RSUP Dr. HASAN SADIKIN BANDUNG
FACULTY OF MEDICINE UNPAD - Dr. HASAN SADIKIN GENERAL HOSPITAL BANDUNG
KOMITE ETIK PENELITIAN KESEHATAN
THE HEALTH RESEARCH ETHICS COMMITTEE

KETERANGAN PERSETUJUAN ETIK
ETHICAL CLEARANCE

No.: 123 /FKUP-RSHS/KEPK/Kep./EC/2008

Komite Etik Penelitian Kesehatan Fakultas Kedokteran Universitas Padjadjaran – RSUP Dr. Hasan Sadikin Bandung, dalam upaya melindungi hak asasi dan kesejahteraan subjek penelitian kesehatan dan menjamin bahwa penelitian berjalan sesuai dengan pedoman ICH-GCP dan aturan lainnya yang berlaku, telah mengkaji dengan teliti dan menyetujui proposal penelitian berjudul:

The Health Research Ethics Committee of Medical Faculty of Padjadjaran University - Dr. Hasan Sadikin General Hospital Bandung,in an effort to protect the basic rights and welfare of the subject of the health research and to assure that a research operates in accordance with ICH-GCP *guidelines and other applicable laws and regulations, has thoroughly reviewed and approved a research proposal entitled:*

"PERAWATAN BERBASIS BUDAYA MUSLIM BAGI ORANG HIDUP DENGAN HIV/AIDS DI BANDUNG, INDONESIA"
"MUSLIM CULTURAL CARE FOR PEOPLE LIVING WITH HIV/AIDS IN BANDUNG, INDONESIA"

Nama Peneliti Utama : Kusman Ibrahim, S.Kp., MNS
Name of the principal investigator

Nama Institusi : Fakultas Ilmu Keperawatan Unpad
Name of institution

Ditetapkan di : Bandung
Specified in
Tanggal : 19 September 2008
Date

Ketua,
Chairman,

Prof. H. Herry Garna , dr, SpA.K,Ph.D
NIP. 130 321 221

Sekretaris,
Secretary,

Prof. Dr. Johanes C. Mose, dr, SpOG-K
NIP. 140 086 935

APPENDIX K

VITAE

Name Mr. Kusman Ibrahim
Student ID 5010430009

Educational Attainment

Degree	Name of Institution	Year of Graduation
Bachelor of Science in Nursing	Padjadjaran University	1998
Master of Nursing Science	Prince of Songkla University	2004

Scholarship Awards during Enrolment

- PSU President Scholarship for PhD degree
- The Directorate General of Higher Education, Ministry of National Education, Indonesia

Work – Position and Address

Lecturer, Faculty of Nursing, Padjadjaran University, Bandung, Indonesia
Phone: +62 22 779xxxx E-mail: kusman_ibrahim@yahoo.com

List of Publications and Proceedings

Publications:

Ibrahim, K. (2005). Quality of life of hemodialysis patients and their spouses. *Bandung Medical Journal*, 37(3): 99-104

Ibrahim, K., Taboonpong, S., & Nilmanat, K. (2009). Coping and quality of life among Indonesians undergoing hemodialysis. *Thai Journal of Nursing Research*. 13(2): 109-116

Ibrahim, K., & Songwathana, P. (2009). Cultural care for people living with HIV/AIDS in Muslim communities in Asia: a literature review. *Thai Journal of Nursing Research*. 13(2): 148-156

Ibrahim, K., Songwathana, P., Boonyasopun, U., & Francis, K. (2010). The HIV/AIDS epidemic in Indonesia: Does primary health care as a prevention and intervention strategy work? *International Journal of Nursing Practice*. 16: 87-91

Proceedings:

Ibrahim, K., Songwathana, P., & Boonyasopun, U. (2009, August 9-13). Empowering self: Caring expressions of Injecting Drug Users living with HIV/AIDS in Bandung Indonesia. Poster presentation at *the 9th International Congress on AIDS in Asia and the Pacific*. Bali International Convention Center, Nusa Dua, Bali, Indonesia

Ibrahim, K., Songwathana, P., Boonyasopun, U., & Francis, K. (2009, August 17-22). Living with HIV/AIDS: An ethnographic study in the Bandung Muslim Community, Indonesia. Poster presentation at *the "Research Matters", High Degree Research Poster Presentation*, Monash University, Gippsland, Australia

Ibrahim, K., Songwathana, P., & Boonyasopun, U. (2009, October 21-22). Culture care for people living with HIV/AIDS in Muslim community of Bandung, Indonesia. Oral presentation at *the 3rd International Nursing Conference & Workshop 2009, Internationalization of Nursing Education: Challenging future for nursing services*. Mercure Hotel Ancol, Jakarta, Indonesia.

Ibrahim, K., Songwathana, P., & Boonyasopun, U. (2010, April 7-9). Caring and living with HIV/AIDS in Muslim community of Bandung, Indonesia. Oral presentation at *the 2010 International Nursing Conference "Diversity and Dynamic of Nursing Science and Art"*. Phuket Graceland Resort & Spa, Phuket, Thailand.

Ibrahim, K., Songwathana, P., & Boonyasopun, U. (2010, April 10). Submitting self to Allah: Care perception of persons living with HIV infection in Muslim community of Bandung, Indonesia. Oral presentation at *the 2nd International Conference on Humanities and Social Sciences*. Faculty of Liberal Art, Prince of Songkla University, Hatyai, Thailand.