

LIVING WITH HIV/AIDS IN A MUSLIM COMMUNITY: AN ETHNOGRAPHIC STUDY IN BANDUNG, INDONESIA*

Kusman Ibrahim¹, Praneed Songwathana², Umaporn Boonyasopun³

¹Lecturer Faculty of Nursing, Padjadjaran University, Bandung, Indonesia

²Associate Professor, RN, PhD, Faculty of Nursing, Prince of Songkla University, Hat Yai, Thailand

³Assistant Professor, RN, PhD, Faculty of Nursing, Prince of Songkla University, Hat Yai, Thailand

*Manuscript was presented in The 3rd International Nursing Conference & Workshop 2009, Internationalization of Nursing Education: Challenging future for nursing services, 21-22 October 2009, Faculty of Nursing, University of Indonesia, Jakarta, Indonesia.

INTRODUCTION

Acquired Immune Deficiency Syndrome (AIDS) has reached pandemic proportions affecting millions of people men, women, and children around the world. There were an estimated 33.2 million people living with Human Immunodeficiency Virus (HIV) and AIDS in 2007 worldwide, and most of them live in developing countries. 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). The HIV pandemic is still a major problem and poses continual challenges to every country, regardless regions and/or cultural beliefs (Fauci, 1999).

Indonesia is a developing country which a predominantly Muslim. Population has been facing increasing numbers of PLWH since the first case was identified in 1987. The country is known as having the fastest growing HIV epidemic in Asia (UNAIDS, UNICEF, WHO, & ADB, 2008). The estimated number of PLWH was reported in 2001 as 93,000 and has since increased to 270,000 at the end of 2007 (WHO, UNAIDS, & UNICEF, 2008). Unless prevention programs are effective, it is

predicted that the prevalence of HIV would reach 500,000 by the end of 2010 (MoH, 2006) and 1 million by 2015 (AusAID, 2006). Bandung has the highest number of reported HIV/AIDS cases (MoH, 2009). The city with its 2.5 million inhabitants is located about 180 km southeast of Jakarta, the capital of Indonesia. HIV/AIDS reported in Bandung is predominantly found among injecting drug users rather than in other risk groups (Bandung AIDS Control Commission., 2007).

Cultural beliefs with regard to health and illness are important factors in creating stigma and discrimination toward people who are living with a particular disease (Link & Phelan, 2001). For example, in a Muslim community, the social stigma attaches to HIV/AIDS is much more pronounced due to the religious doctrine condemning extramarital sex, homosexuality, and illicit drugs (Hasnain, 2005). Previously, many Muslims believe that they were protected from HIV/AIDS due to their religious and cultural norms. However, in certain circumstances, risky behavior that leads to HIV infection, although prohibited by Islam, is practiced by some Muslims. Consequently, HIV viruses do not only enter to body of people who engage with those risky behaviors, but may also be transmitted to innocent people as their wives and children.

A number of studies have been focused on the impact of HIV and AIDS experienced by HIV-infected persons and caring for those patients experienced by nurses. Culture is acknowledged as a major determinant in caring for HIV persons (Lee, Keiwkarnka, & Khan, 2003; Wolfers, 1997). However, most studies on HIV and AIDS were conducted in Western and often lacked the Muslim context. This is why little is known about how persons with HIV/AIDS living in cultural context of Muslim community particularly in Indonesia. This paper reported the preliminary

findings of a large ethnographic study that aims to gain an in-depth understanding of phenomenon of living with HIV/AIDS in Muslim community of Bandung, Indonesia. The findings of the study may provide a valuable knowledge to develop a culturally appropriate of care for persons living with HIV/AIDS.

METHOD

This study utilizes a focused ethnography approach to discover, describe, and systematically analyze the cultural contexts of caring and living with HIV/AIDS in Muslim community of Bandung, Indonesia. Leininger (1985; 2002) stated that the focus ethnography or 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 living with HIV/AIDS in the cultural context of Muslim community of Bandung, Indonesia.

To gain trust of informants and allow contextual understanding of the phenomenon under investigation, the first researcher who is an Indonesian had immersed in the naturalistic setting. The NGOs' staffs working for HIV/AIDS served as gatekeepers facilitating access to participants. Human relation skills and fluency speaking in both Indonesian and Sundanese language (local language) of the first researcher has greatly facilitated winning the trust of the informants. The role as a primary instrument required reflexivity from the researcher. It means the researcher deliberately use of "self" in data collection and analysis while being aware of the ways in which "self" affects both the research process and its outcomes (Roper & Shapira, 2000). Thus, the researcher had to keep his preconceptions and values aside

throughout the research process while intimately interacting with informants and the data.

Twelve people living with HIV/AIDS participated in this study. Data were collected through participant observation and individual interviews. Data generated were analyzed using a variety of techniques included thematic and content analysis, constant comparative data analysis, discourse analysis and member checking. The process of data analysis in this study involved four steps as recommended by Leininger (2002) included (1) collecting, describing, and documenting raw data, (2) identification and categorization of descriptors and components, (3) identification pattern and contextual analysis, (4) formulation themes and research findings. The findings of this study were evaluated by the process of credibility, confirmability, and transferability as suggested by Lincoln and Guba (1985).

FINDINGS

The informants shared their insight into living with HIV/AIDS. The social and economic hardships as well as the religious cultural norms of the society have shaped their fruitful experiences in caring and living with the ‘scared illness’. Six themes were emerged from the informants related to their experience in living with HIV/AIDS in this study. They were: (1) quitting out from injecting drugs, (2) response of knowing HIV status, (3) symptoms experiences and declining health condition, (4) Help seeking and accessing health care, (5) Dealing with ‘overwhelming’ medications, and (6) coping with day-to-day living with HIV/AIDS. These themes are described as follows:

1. Quitting out from injecting drugs

Being a drug user has imposed a significant burden from the informants' point of view. Informants involved in drugs user, they initially just trial for fun and to be accepted in their peers. Once they have tried the stuff, they became addicted for the rest of their life. It was hard for them to quit from the stuff unless they have a strong intention or motivation to leave it. Here are the statements from the informants:

I feel like living in a new life in the real world after quitting from drugs user. Previously I felt live under shadows which my mind was always filled by thinking about the drugs...I have my own world, the world of imagination, every times just thinking how to get drugs... these made me tired and exhausting...(K1).

2. Response of knowing HIV status

The informants responded to the diagnoses of HIV positive can be divided into sub-themes including shock, despair and hopeless, and reconditioning the rest energy for life. Each sub-theme is described as follows:

2.1 Shock

The informants who unrealized that HIV may possible to enter their body with various ways; they were shocked when they knew that they were positive. As an informant said:

When I learned from the test that I was positive, I was shocked and very sad. I did nothing for more than six months until I recognized something wrong with my body...(K2)

2.1 Despair and hopeless

Despair and hopeless of the informants mostly due to perceive severity of the illness since they witnessed serious symptoms accompanying the illness. An informant said:

I observed my health condition became worse and worse...when the doctor told me that I was HIV infected...oh...I almost despair and hopeless, I did not think that he would recover...(K1)

2.2 Reconditioning the rest energy for life

Shock and stressful as the informants knew their status imposed emotional burden to the psychological well being. Some informants knew their status in the advance stage of the illness which developed symptoms of fatigue and weakness. However, they attempted to manage the rest of energy to continue their life. As the informants said:

I was very sad when I was told that I was positive, I could not retain the tear was flowing from my eyes...I just keep stay at bedroom most the time, it seemed no energy to going out... (K7)

3. Symptoms experienced and declining health condition

Along with declining health condition, the informants experienced various symptoms of the illness. Most of the symptoms were weakness, losing body weight due to persistent diarrhea, or chronic coughing due to lung infection. Skin rashes, itching, and other types of infection were reported by the informants as expressed the following:

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 to get sick on the following days such as ears infected by worms, eyes infected, itching, and diarrhea that losing my weight (K2)

4. Help seeking and accessing health care

As other people, the informants utilized the existing health care facilities including community health centers (CHC) and hospitals for seeking help. The CHCs were the first choice to be visited due to low cost and widely available in the

city. However, not all the CHCs offered VCT (Voluntary Counseling and Testing) service for HIV/AIDS due to limited number of counselors. The informants visited CHC after developing particular symptoms; even they came to hospital in the advance stage of illness. Some informants sought traditional healing to help alleviating their symptoms. The informants said:

I have no money to go to hospital, so my sister took me to the natural hot spring with hope to heal my skin rashes and itching (K2)

5. Dealing with ‘overwhelming’ medications

Dealing with a lot of pills and side effects of medication has been a major concern among the informants. Most of symptoms experienced due to the side effects of TB and ARV medications were nausea, vomiting, dizziness, and insomnia. As stated by the following informants:

At the beginning of taking ARV medications, I experienced nausea, dizziness, and unable to get sleep well at night. So, it was really unpleasant and I almost stopped it, yet I gradually became more tolerance with the pills (K8)

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

6. Coping with day-to-day living with HIV/AIDS

HIV/AIDS has brought a remarkable impact to the daily living of the informants. Problems associated with the illness have challenged the informants to be able to cope with those in order to live well. There were three sub-themes reflected the coping used by the informants: not think too much and let the life go naturally; making busy with daily activities; and keeping healthy life styles. Each sub-theme was described as follow:

6.1 Not think too much, let the life go naturally

The informants aware that too much concern about their illness would not solve the problems effectively, instead of resulted additional burden for them. They tried to avoid this thing and just let everything go naturally. The informants said:

Sometime, the more I know the illness the more stress I get...so I just let everything going on and not think too much about the illness... (K3).

6.2 Making busy with daily activities

Making busy with the daily life activities have been considered as an effective strategy to distract the informants' thought from thinking about the present illness.

As the informants said:

Most of the time I spend for doing household works and looking after my kids and my sister's kids...so just make myself busy every days...sometime I forget that I have the illness (K2).

I just make myself busy with the daily activities such as doing home works, taking care children, and involving in NGO's activities to forget my illness... (K3)

6.3 Keeping healthy life styles

The informants have been informed the importance to practice healthy life styles either by NGO or health care providers. The practices included taking medicines without missing, not too much stress, maintain balance between activities and rest, hygiene, and good nutrition. Accessed to good nutrition was still the main concern of the most informants due to financial constrains. Informants with IDU's background were also still unable to quite from smoking and even drinking alcohol.

The informants said:

It is alright with the fact that I live with HIV...the important thing that I has never done anything wrong or misconduct behaviors... I believe God will help me as long as I pray Him and keep efforts by practicing healthy life styles such as taking medications without missing and avoiding too much stress... (K11)

Since I learned that people with this illness was susceptible to get other infections...so I tried to practice healthy life styles as much as I could such as maintain hygiene, no smoking, kept balance between activities and rest, good nutrition, and not too much stress...yet for good nutrition is quite difficult for me since I have no fix income... (K3)

DISCUSSION

The findings of this study highlighted a valuable experience of living with HIV/AIDS. The serious symptoms experienced by PLWH that amplified by the perceived stigma about the illness has drawn significant effect on informants to quit from the drugs which considered as the main route of getting infection. The nature of HIV illness has changed from acute-fatalistic disease to chronic-manageable disease due to the advancement of antiretroviral therapy. This required PLWH to develop self-care strategies to maintain their health and well-being. Previous studies demonstrated 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; there were dealing with rural issues, staying healthy, and way of taking care of self with HIV. Both studies were conducted in a Secularized Western cultural setting which commonly people less concern about religion in their life.

Shambley-Ebron and Boyle (2006) discovered something contrast 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 role of mothering to maintain health instead of practicing certain behaviors as prescribed by health care providers. In this study, the informants demonstrated utilizing both approaches; cultural beliefs based self-care and in some degree utilizing prescribed health care providers self care. Three categories of self-care were presented in this study, these were promoting health and well-being, relieving HIV-related symptoms, and reducing family care burden.

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

Besides utilizing self-care strategies based on cultural religious belief; such as “*pasrah* (submission)” and prayer to promote health, PLWH also utilize various self-care methods to relieve symptoms. The self-healing methods were commonly developed based on trial experience or recommended by family or friends. Several earlier studies reported on investigation self-healing or self-management methods to relieve HIV-related symptoms. Rose, Pugh, Lears, and Gordon (1998) found PLWH who experienced fatigue used 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 remaining energy level. Eller et al (2005) reported some PLWH in their study used prayer, meditation or relaxation, and reiki as self-healing methods to manage symptoms.

Using complementary/alternative therapies has been chosen by the informants as a way to relieve symptoms. The reasons of using the therapies were mostly due to uncertainty with the modern medicine, easily available in their area, affordable price, fewer side effects. This indicated that PLWH still maintain belief toward their cultural rooted therapies to heal their illness. This phenomenon was not only happened in the Eastern countries which people mostly have strong bonding to their cultural heritage and tradition, but also in the Western countries. Corless et al. (2002) reported some PLWH used complementary therapies such as acupuncture, meditation. While 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 become the main option for most PLWH to heal their illness or reliving symptoms. Gaskins and Lyons (2000) that reported PLWH rely on physician in the HIV clinic for their treatment though some of them were bothered by feeling shame due to many people know they attend the HIV clinic. Additionally, Irwanto and Moeliono (2007) reported that among 270 surveyed PLWH, about two-third of them visited health care service to obtain ARV, VCT, and nursing care though some of them encountered barriers such as feeling of fear to be known by relatives or friends, or fear of rejection by health care providers due to their HIV status.

Antiretroviral remains become the most powerful regimen to limit HIV proliferation in the body though many cases were reported regarding its side effects. The experience of dealing with ARV side effects may lead to discontinue of taking ARV medication. Therefore, maintaining ARV adherence becomes an essential self-care strategy for PLWH to be able to undergo the treatment successfully. Gray (2006) discovered the ways of PLWH in maintain adherence which reflected into several themes such as “choosing life” as 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 et al (2007) interviewed PLWH who 100% adherent, they found that viewing ARV as a life-line, willingness to live longer and healthier, optimal ongoing patient-provider relationship, better coping to side effects, and improvement in clinical condition, are motivating factors for PLWH to remain adherence to ARV treatment.

CONCLUSION AND RECOMENDATIONS

The study highlighted the experience of PLWH which reflect the cultural beliefs and practice of the people. Quitting from injecting drugs was reported as the main point to change the informants’ life since they experienced worse conditions resulted by HIV infection. Their response to knowing HIV status were vary from shock, despair and hopeless, and reconditioning the rest energy for life. As the illness progressed, their health condition was also deteriorating. It has brought them to seek help and access health care services. The overwhelming medication due to various

symptoms experienced by PLWH, has drawn significant impression among PLWH which led them to deal with side effects of the drugs. The ups and down of health status that was augmented by psychosocial consequences resulting from the living with such illness, has forced PLWH to develop various coping strategies to maintain their life and healthy. The findings of the study suggest that nurses and health care providers to need to understand and incorporate the live experience of PLWH in order to provide holistic and comprehensive nursing care for people living with HIV/AIDS.

REFERENCES

- AusAID. (2006). *Impacts of HIV/AIDS 2005-2025 in Papua New Guinea, Indonesia and East Timor* (No. 1 920861 81 5): AusAID.
- Bandung AIDS Control Commission. (2007). *Rencana strategis penanggulangan HIV/AIDS Kota Bandung 2007 - 2011 (Strategic planning for HIV/AIDS control in Bandung 2007-2011)*.
- Bhattacharya, G. (2004). Health care seeking for HIV/AIDS among South Asians in the Unites States. *Health & Social Work, 29*, 106-115.
- Corless, I. B., Bunch, E. H., Kempainen, J. K., Holzemer, W. L., Nokes, K. M., Eller, L. S., et al. (2002). Self-care for fatigue in patients with HIV. *Oncology Nursing Forum, 29*(5), 60-68.
- Duffy, L. (2005). Suffering, shame, and silence: The stigma of HIV/AIDS. *Journal of the Association Nurses in AIDS Care, 16*, 13-20.
- Eller, L. S., Corless, I., Bunch, E. H., Kempainen, J., Holzemer, W., Nokes, K., et al. (2005). Self-care strategies for depressive symptoms in people with HIV disease. *Journal of Advanced Nursing 51*(12), 119-130.

- Fauci, A. S. (1999). The AIDS epidemic, consideration for the 21st century. *The New England Journal of Medicine*, 341(14), 1046-1050.
- Gaskins, S., & Lyons, M. A. (2000). Self-care practices of rural people with HIV disease. *Online Journal of Rural Nursing and Health Care*, 1(1), 18-27.
- Gray, J. (2006). Becoming adherent: Experiences of persons living with HIV/AIDS. *Journal of the Association of Nurses in AIDS Care*, 17(3), 47-54.
- Hasnain, M. (2005). Cultural approach to HIV/AIDS harm reduction in Muslim countries. *Harm Reduction Journal*, 2(23).
- Irwanto, & Moeliono, L. (2007). *ODHA dan akses kesehatan dasar, penelitian partisipatif (PLWHA and access to primary health care, participatory research)*. Jakarta: National AIDS Commission.
- Lee, K., Keiwkarnka, B., & Khan, M. I. (2003). Focusing on the problem instead of the solution: How cultural issues in North Thailand continue to influence HIV/AIDS infection and infected patients' quality of life and treatment by health providers. *Journal of Public Health and Development*, 11(1), 119-134.
- Leininger, M. (1985). *Qualitative research methods in nursing*. Orlando: Grune & Stratton, Inc.
- Leininger, M. (2002). Essential transcultural nursing care concepts, principles, examples, and policy statements. In M. Leininger & M. R. McFarland (Eds.), *Transcultural nursing: Concepts, theories, research, & practice* (Third ed., pp. 45-70). New York: Mc Graw-Hill Medical Publishing Division.
- Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, 27, 363-385.
- Ministry of Health of the Republic of Indonesia. (2006). Peringatan hari AIDS sedunia 2006, "Stop AIDS: Saatnya Melayani!". Retrieved July 29th, 2007, from <http://www.depkes.go.id>

- Ministry of Health of the Republic of Indonesia. (2009). Statistics of HIV/AIDS cases in Indonesia until March 2009. Retrieved May 13th, 2009, from <http://www.depkes.go.id>
- Roper, J. M., & Shapira, J. (2000). *Ethnography in nursing research*. Thousand Oaks: Sage Publications, Inc.
- Rose, L., Pugh, L. C., Lears, K., & Gordon, D. L. (1998). The fatigue experience: persons with HIV infection. *Journal of Advanced Nursing*, 28, 295-304.
- Shambley-Ebron, D. Z., & Boyle, J. S. (2006). Self-care and mothering in African American women with HIV/AIDS. *Western Journal of Nursing Research*, 28(1), 42-69.
- Sidat, M., Fairley, C., & Grierson, J. (2007). Experiences and perceptions of patients with 100% adherence to Highly Active Antiretroviral Therapy: A qualitative study. *AIDS Patient Care and STDs*, 21(7), 509-520.
- UNAIDS, UNICEF, WHO, & ADB. (2008). Country review: Indonesia, evidence to action. Retrieved April, 21, 2009, from www.aidsdatahub.org
- UNAIDS, & WHO. (2007). AIDS epidemic update: December 2007. Retrieved April 10, 2008, from www.unaids.org
- WHO, UNAIDS, & UNICEF. (2008). Epidemiological fact sheet on HIV and AIDS, core data on epidemiology and response: Indonesia, 2008 update. Retrieved January, 14, 2009, from <http://www.unaids.org>
- Wolffers, I. (1997). Culture, media, and HIV/AIDS in Asia. *Lancet*, 349, 52-54.