Cultural Care for Women with HIV/AIDS in Northeastern Thailand

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Until 1987, when a much publicized HIV/AIDS-related case involving a factory worker got the infection from blood transfusion, the oft-believed association of the infection with promiscuity was given a human factor as potential cause. Studies such as this rid much of the fears that immobilized many HIV/AIDS positive people to look beyond their condition. Providing an acceptable cultural meaning of HIV/AIDS will certainly contribute to effective cultural care management for women living with HIV/AIDS in their natural context, thus continually empowering them to look after themselves with neither fear nor paranoia.

Acquired immunodeficiency syndrome (AIDS) which is caused by Human immunodeficiency virus (HIV) is currently an important worldwide health problem. HIV/AIDS remains the leading cause of adult death worldwide (Merson, 2006; Rhucharoenpornpanich & Chamratrithirong, 2001; UNAIDS, 2006; WHO, 2003). Complex medical, social, economic, political and ethical concerns surrounding HIV/AIDS challenge those who are involved in dealing with the issue. Moreover, requirement for treatment are increasing the demand worldwide for health resources (Danziger, 1994; Li et al., 2007; UNAIDS, 2004).

A beneficial study has been conducted to explore the ways in which Thai women with HIV/AIDS take care of their health and manage their lives in the context of stigma and discrimination (Nilmanart, Street, & Blackford, 2006; Phengjard, Brown, Swansen, & Schepp, 2002; Singhanetra-Renard, Chongsatitmun, & Aggleton, 2001; Sringernyuang, Thaweesit, & Nakapiew, 2005; UNAIDS, 2004). Moreover, the study focus on the cultural care management of Thai women living with HIV/AIDS , thus providing them the knowledge to manage self-care, based on the Thai Isaan women perspective.

An All-time Epidemic

The HIV/AIDS epidemic in Thailand has affected all sectors of Thai society, although the number of new HIV/AIDS cases per year decreased from more than 130,000 in the early 1990s to fewer than 20,000 cases in 2003 (Sunthrajarn, Wongkongkathep, Onnom, & Amornwichet, 2005). Currently, the number of new HIV/AIDS infections is estimated to be about 17,000 cases a year (MOPH, 2007a). There are many people living with HIV/AIDS, an increasing number of whom are beginning to show symptoms from opportunistic infectious diseases associated with the disease.

Thus, during the period of the inception, data collection and conduct of this study, changes in health policy have enabled Thai people with HIV/AIDS to live longer because they can now more readily access healthcare service and antiretroviral therapy (MOPH, 2007a, 2007b; MOPH & World Bank, 2006). However, in addition to healthcare and medication, people living with HIV/AIDS need a wide range of cultural care management strategies to deal with the condition and life events in their home.

Method of the Study

Ethnographic methodology was utilized as an appropriate approach to explore the ways that Thai women with HIV/AIDS take care of their health and manage their lives in the context of stigma and discrimination. This methodology was used because this allowed a focus on the description and interpretation of community behaviour and social or cultural systems (Spradley, 1979; Nakagasien, Nuntaboot & Sangchart, 2008). Cultural perspective was used to emphasize the conceptual system of women with HIV/AIDS.

One provincial hospital was selected as the study site from which to recruit participants. It is a large public healthcare institution that provides services to clients from both urban and rural areas in that province and the nearby areas. The hospital extends its healthcare services in an HIV/AIDS day care clinic from Monday to Friday, 8.00 a.m. to 4.00 p.m. to cater to HIV/AIDS-positive individuals.

The participants in this study were 20 HIV/AIDS-positive females from one rural community in Northeastern Thailand, and selected from among the patients who lived at home and attended the HIV/AIDS day care clinic in one provincial hospital. Initially, three participants were recruited purposively from the HIV/AIDS day care clinic. The criteria for selecting participants included people who:

1) were diagnosed with HIV infection by having an HIV-seropositive test;
2) accepted that they were HIV/AIDS- positive ;
3) were able to communicate in–and understand–the Thai language; and,
4) were willing to participate in the study.

In this study, data collection methods included in-depth interviews, participant observations, field notes made during home visits, and reviewing health records in the clinic. The process spanned for eight months (between April 2008 and November 2008).

The process of data analysis included first coding substantively. Each field note, transcription, or document was read line by line with the questions; and the coding, analysis of data and themes selected as statements were relevant to the cultural care for woman with HIV/AIDS. Results of the Study The results of this study were presented in two parts:

1) cultural meaning of HIV/AIDS, and,
2) the finding of cultural care management for Thai women living with HIV/AIDS.

1) Cultural Meaning of HIV/AIDS

Understanding, perception and meaning of being HIV/AIDS-positive became clear. After participants received the diagnosis, they began to accept their condition. Some participants had initially suspected they had HIV/AIDS when they observed signs and symptoms that appeared on their body. Others were diagnosed when they were admitted to hospital for treatment of opportunistic diseases such as pulmonary tuberculosis (TB), fungal meningitis, or pnuemocystic carinii pneumonia (PCP). Having HIV/AIDS, which reflected the participants' belief in the socio cultural context of Isaan was supported by codes including *experiencing symptoms, incurable, expect to die soon, and communicable.*

Experiencing symptoms

When the condition of an HIV/AIDS-positive person changed from asymptomatic to symptomatic illness, distress and discomfort were experienced. Her recourse was to seek help from the physician and others for care management. For example, one participant stated:

> *"I got white patches in my mouth, I couldn't eat, and it hurt my mouth. I lost weight, was thin and fatigued and couldn't walk. My friend took me to the community hospital; I was admitted for 2 weeks with AIDS-related symptoms.... My immunity was low, (CD4+ was 1).... I had to take antiretroviral drugs...to control the HIV virus... (P) "*

Incurable (ruksa bor souw)

Most participants learned from the media, health professionals and their own experience that HIV infection and AIDS were disease that had no vaccine or medicine for a cure.

> *" I knew AIDS was not curable; many people in the village talked about people who had AIDS must die. I would become sick and die ... (F) "*

Expect to die soon (taay wai)

Most participants believed not only that HIV/AIDS was a fatal disease, but also that people who were infected would die soon. Most of the participants had seen people with AIDS die after a relatively short and severe illness. Thus, after the participants had been diagnosed positive of HIV/AIDS they felt hopeless. Most of the participants expressed the fear that they would *"taay wai" (die soon), "tong taay nae" (must die for sure)* or were *"yaan taay" (afraid to die)* when they were describing coming to terms with having HIV/AIDS. Some participants stated that:

"When I got serious illness, I was admitted at the hospital. I thought I must die for sure. I knew my disease is serious and death comes quickly, I have heard from the radio about AIDS patients who must die for sure and I was afraid to die... (H)"

Communicable (roke tid tor)

Most of the participants identified that HIV/AIDS was a disease associated with sexual contacts by having experiences with prostitutes.

"AIDS is a "roke tid tor" (communicable disease) and it is transmitted by sexual intercourse with females who are bad persons or females who sell sex... (R) "

The participants initially understood HIV/AIDS as an experiencing symptom; incurable; foreboding one to expect to die soon; and a communicable disease that is survivable only for a short period of time.

2) The Finding of Cultural Care Management for Thai Women Living with HIV/AIDS.

The results of this study, revealed the context of cultural care management of women with HIV/AIDS. As participants came to accept their condition and learnt of HIV/AIDS as a chronic disease rather than as a rapidly fatal illness, they turned their attention to learning how to maintain their health and manage their situation to live as satisfying a life as possible. Cultural care management strategies include acceptance of having the disease, participation in religious practices, and sustaining hope.

Accepting the disease

The participants accepted that HIV/AIDS was a chronic illness when they learned from their experiences that they were not able to get rid of their illness.

"I have learned that AIDS is one of the most deadly diseases, and if I take good care of myself, I can live longer because I saw some AIDS person live longer for 16 years and he looked healthy like normal people. Now I think that it is as chronic a disease as "bouw waan" (Diabetes mellitus) and "kuam done lo hid sung" (Hypertension), so there is no cure for the AIDS disease... (A)"

Religious practices

Religious practices helped HIV/AIDS-positive individuals to maintain their perspective in life and to experience comfort, peace and happiness.

" I practice meditation by sitting and doing breathing exercises. On breathing in I say "phut" and when breathing out I say "tho". After about 20 minutes I have peace of mind and I sleep well until morning. I believe that having peace can result in better health. I have heard the monks teach this when they preach at the temple on holy days... (S)"

Having hope

All participants in this study hope for positive changes and good things to happen in the future. Moreover, participants perceived that hope was essential to their life because having hope helps them to manage their disease and they can go on with life despite having HIV/AIDS.

" I must make myself get well. I don't think too much; if I think too much the CD4+ would be down. I think I can live longer, as long as possible with my family... (A)"

Hope is one of the forces that motivated the participants to keep trying to reach their goals. Goals are key to purposive behaviour and effective management of their lives.

Discussion and Conclusion

The study result illustrates how the nature of perceptions and understanding of HIV/AIDS positive Thai women on the condition affected the cultural care management for women with HIV/AIDS in Isaan community. Beliefs about AIDS as a disease of experiencing symptoms, that is incurable and communicable, and makes one expect to die soon were held by participants (Siriwatanamethanon, Boddy, Dignam, & Nuntaboot, 2008).

As participants learnt that HIV/AIDS can actually be managed, if not cured – at least for now, they needed to develop strategies to deal with their internalised social disgust as well as the potentially discriminatory responses of others (Siriwatanamethanon, Boddy, Dignam, & Nuntaboot, 2008).

All participants had to actively manage their conditions to sustain their health and recover from their illness. Religion helped them to have that strength. Chinouya and O' Keefe (2005) reported that finding inner strength by religion helped Africans living with HIV to cope with the disease, while Chammas (1999) suggested that sustaining hope may improve quality of life. Thus, participants tried to maintain or reestablish religious practices in their life, helping them avoid the anxiety of their condition, and consequently allow them to continue life in the society (Siriwatanamethanon, Boddy, Dignam, & Nuntaboot, 2008).

Acceptance was critical to participants to enable them to have hope and to maintain their health (Siriwatanamethanon, Boddy, Dignam, & Nuntaboot, 2008). The result of hope is the energy to work for the future (Holt & Reeves, 2001). Hope is influenced by the sociocultural environment and is dependent on managing the risk of stigma and discrimination within that environment (Siriwatanamethanon, Boddy, Dignam, & Nuntaboot, 2008).

The results of this study are useful for health professionals, providing them with a clearer concept of the cultural care management among Thai women with HIV/AIDS, and which can be applied and integrated by health professionals into nursing practice, nursing education and further research for people living with HIV/AIDS. ■

References

Chammas, G. Y. (1999). *Hope, functional status, and quality of life in hospitalized patients with human immunodeficiency virus infection and acquired immunodeficiency syndrome*. Abstract, Retrieved November 13, 2007, from http://web.ebscohost.com.ezproxy.massey.ac.nz/ehost/delivery?vid=7&hid=17&sid=e...

Chinouya, M., & O' Keefe, E. (2005). God will look after us: Africans, HIV and religion in Milton Keynes. *Diversity in Health & Social Care, 2*(3), 177-186.

Danziger, R. (1994). The social impact of HIV/AIDS in developing countries. *Social Science & Medicine, 39*(7), 905-917.

Holt, J., & Reeves, J. S. (2001). The meaning of hope and generic caring practices to nurture hope in a rural village in the Dominican Republic. *Journal of Transcultural Nursing, 12*(2), 123-131.

Joint United Nations Programme on HIV/AIDS (UNAIDS). (2004). *2004 Report on the global AIDS epidemic 4th global report*. NLM classification: WC 503.4.

Joint United Nations Programme on HIV/AIDS (UNAIDS). (2006). *2006 report on the global AIDS epidemic. A UNAIDS 10 th anniversary special edition*.

Li, L., Lin, C., Wu, Z., Wu, S., Rotheram-Borus, M. J., Detels, R., et al. (2007). Stigmatization and shame: Consequences of caring for HIV/AIDS patients in China. *AIDS Care, 19*(2), 258-263.

Merson, M. H. (2006). The HIV-AIDS pandemic at 25-the global response. *The New England Journal of Medicine, 354*(23), 2414-2417.

Ministry of Public Health (MOPH). (2007a). *Towards universal access by 2010: Thailand national HIV and AIDS program.* Bureau of AIDS, TB and STIs Department of Disease Control. Ministry of Public Health, Thailand.

Ministry of Public Health (MOPH). (2007b). *Analysis of policy development on antiretroviral treatment (ART) services, its advocacy and integration into universal health insurance: Term reference.* Bureau of AIDS, TB and STDs, Department of Disease Control. Ministry of Public Health, Thailand.

Ministry of Public Health (MOPH) and World Bank. (2006). *Expanding access to ART in Thailand: Achieving treatment benefits while promoting effective prevention.* MOPH: Thailand.

Nakagasien, P., Nuntaboot, K., & Sangchart, B. (2008). Cultural care for persons with diabetes in the community: An ethnographic study in Thailand. *Thai Journal of Nursing Research, 12(2)*, 121-129.

Nilmanat, K., Street, A. F., & Blackford, J. (2006). Managing shame and stigma: Case studies of female carers of people with AIDS in southern Thailand. *Qualitative Health Research, 16*(9), 1286-1301.

Phengjard, J., Brown, M. A., Swansen, K. M., & Schepp, K. G. (2002). Family caregiving of persons living with HIV/AIDS in urban Thailand. *Thai Journal of Nursing Research, 6*(3), 87-100.

Rhucharoenpornpanich, O., & Chamratrithirong, A. (2001). Demographic impact of AIDS on the Thai population. *Asia-Pacific Population Journal, 16*(3), 71-88.

Singhanetra-Renard, A., Chongsatitmun, C., & Aggleton, P. (2001). Care and support for people living with HIV/AIDS in northern Thailand: Findings from an in-depth qualitative study. *Culture, Health & Sexuality, 3*(2), 167-182.

Siriwatanamethanon, J., Boddy, J., Dignam, D., & Nuntaboot, K. (2008). *From experiencing social disgust to passing as normal: Self-care processes among Thai people suffering from AIDS.* Unpublished doctoral dissertation, Massey University, Palmerston North, New Zealand.

Spradley, J. (1979). The ethnographic interview. New York.

Sringernyuang, L., Thaweesit, S., & Nakapiew, S. (2005). A situational analysis of HIV/AIDS-related discrimination in Bangkok, Thailand. *AIDS Care, 17*(supplement 2), S165-S174.

Sunthrajarn, T., Wongkongkatehp, S., Onnom, C., & Amornwichet, P. (2005). *Health promotion: The challenge in the prevention and control of HIV/AIDS. In 6th Global Conference on Health Promotion (6GCHP), 7-11August 2005, Bangkok, Thailand, Policy and partnership for action: Thailand context,* (pp. 24-27). Technical Papers.

World Health Organization. (2003). HIV/AIDS: *Confronting a killer*. The World Health Report 2003. Geneva: WHO.