Experiences of Thai Women Caring for Their Husbands Living With HIV/AIDS

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ABSTRACT

TITLE: Experiences of Thai Women Caring for Their Husbands Living With HIV/AIDS

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This qualitative study employed a grounded theory method to generate a theoretical explanation of wives' experience of caring for their husbands living with HIV/AIDS in Thailand. Twenty-five interviews were conducted with twenty women who were the primary caregivers of their HIV infected husbands. The sample was comprised of nine HIV positive women, nine HIV negative women, and two women whose HIV status was unknown. The experience of Thai women caring for their husbands living with HIV/AIDS was viewed as a process of living through a series of sacrifices. By choosing to stay to care for their husbands, these women sacrificed their future goals and opportunities and endured many struggles, including financial despair, loss of connection with their extended families and friends, and fear of impending sickness and death.

Through this sacrificed care-giving these women learned the skills necessary to care for their sick and dying husbands. They helped their husbands and family prepare for death and took on additional, and sometimes, overwhelming responsibilities for the survival of the entire household. They were able to endure this caregiving experience by making sense of their situation within their own beliefs and values as they tried to lead as normal a life as possible. How these women actually did the care-giving and the conditions under which this occurred was influenced by a set of intervening factors, such as, the stage of HIV illness for both the husband and the wife, number and ages of the children, their financial status and the strength of their support system. The outcomes of these processes were both positive and negative, involving consequential effects on themselves and their families as they lived with the isolation, stigma and discrimination levied on them from the larger society. Underlying and embedded within all the concepts and processes identified in the experience of women caring for their HIV positive husbands in Thailand was the overarching umbrella of Thai cultural values and Buddhist beliefs.

This study explicates the processes involved in the caregiving of PLWAs and uncovers the social processes, concepts, and theoretical meanings that explain the phenomenon of Thai women caring for their husbands living with HIV/AIDS. It is hoped that this theoretical explanation will contribute to the advancement of nursing knowledge and clinical practice in HIV/AIDS care in Thailand.

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INTRODUCTION

Acquired immunodeficiency syndrome (AIDS) is an infectious disease, which is caused by the human immunodeficiency virus (HIV). HIV/AIDS is a serious threat to public health in many countries and this is particularly true in Thailand. The HIV/AIDS epidemic began in Thailand in 1984, with early transmission limited mainly to the homosexual community. Since the beginning of the 1990s, HIV infection has become more widespread in Thailand, affecting other high-risk populations, especially intravenous drug users and female commercial sex workers (Surasiengsunk et al., 1998). Currently, heterosexual contact via the commercial sex industry is the primary route of HIV transmission in Thailand. Increasingly, HIV is passed from men, who visit commercial sex workers or use injecting drugs, to their female partners (wives, girlfriends) and infants (Inter-country Consultation for Preparation for ASEAN Summit, 2001).

Despite intensive efforts to prevent the spread of HIV infection over the past two decades, HIV/AIDS continues to be the leading social and public health problem in Thailand. In the year 2000, it was estimated that 984,000 Thai people, representing nearly 1.61% of the total population of 61 million, were infected with HIV since the beginning of the epidemic. Of those, 289,000 have died of AIDS (Thai Working Group on HIV/AIDS Projection, 2001). Among those living with HIV/AIDS, more than half are men, approximately 40 % are women, age 15-49 years old, and two percent are children younger than 15 years old (UNAIDS/WHO Working Group on Global HIV/AIDS and STI Surveillance, 2000). Even though the HIV infection rate has currently decreased (approximately 30,000 new infections in the year 2000), due to effective prevention programs, there remain many HIV infected individuals. The number of AIDS cases increases each year because individuals who were infected in the past 5 to 10 years are now developing AIDS symptoms (Ministry of Public Health, 1999). In 2000 alone, due to a limited access to anti-viral medication, it is estimated that 55,000 persons living with HIV/AIDS (PLWAs) will develop serious AIDS related illnesses which require extensive and expensive medical care (Thai Working Group on HIV/AIDS Projection, 2001). It is also estimated that nearly 50,000 Thai people will die of AIDS each year in the next five years due to inadequate medical treatment (Ministry of Public Health, 2001).

The increasing number of AIDS patients reflects a great demand for services from the health care system. Because of the sparse health care resources, the institutional facilities soon will not be able to provide care for all AIDS patients (Kraisurapong, 1998). Therefore, to cope with its limited budget and resources, Thai families are encouraged by the government to provide care for the HIV infected family member at home. Because PLWAs in Thailand are often abandoned by their families due to the social stigma about HIV/AIDS, Thai authorities have recently focused on encouraging Thai people to have compassion and accept the PLWAs within their families and communities, so they can receive the care and support they need and to also reduce the cost of care.

Background

As more families assume responsibility for the care for PLWAs, HIV/AIDS family caregiving becomes a significant issue in health care. As the first step in this researcher's program of research, the researcher conducted case study research on ten families living with HIV/AIDS in Thailand to examine their stressors, strengths, and social support. The study results substantiate the previous evidence of the extreme physical, emotional, and economic challenges facing HIV/AIDS caregiving. Families struggled with multiple stressors while caring for their family member living with HIV/AIDS. The complex demands of care, in addition to the unpredictable illness trajectory, created stress and burden in these families. The stigma of HIV/AIDS and social discrimination clearly affected the families and caregivers of PLWAs. This growing fear of discrimination forced most families to live lives of secrecy, social isolation, and insufficient emotional and financial support. Poverty, the high cost of medical care, loss of income, limited social welfare resources, and the absence of comprehensive medical insurance, contributed to the profound economic burden on family caregivers (Ruangjiratain, 2002).

Traditionally, in Thailand, female family members carry the responsibility as care providers for family members who become ill. As such, Thai mothers, sisters, and wives provide almost 100% of the care for PLWAs. Because HIV infection is more widespread among the heterosexual sex industry participants, more husbands are contracting the disease resulting in their wives becoming their primary caregiver (Janjarat, 1994; Muecke, 2001; Songwathana, 2001). This study will explore the special challenges facing the wife caregivers for their husbands living with HIV/AIDS.

In Thailand, female spouses face unique challenges. Thai wives are usually required to fulfill multiple cultural and social roles. When their husbands become ill, Thai women immediately assume the roles of wife, caregiver, mother, family leader, wage earner, and secret keeper, in addition to becoming ill themselves. Moreover, most Thai women fulfill these roles and responsibilities without sufficient family, social, or economic support. All too frequently, many wives also discover that they or their children have also become infected with HIV. Pregnancy adds another layer of strain given the probability of passing HIV to their child while also worrying about their own and their husbands' deteriorated health. As caregivers, these women are forced to not only struggle with the burden of being a wife, mother, and caregiver, but to become intimately aware of how their own life will end. Another devastating aspect is that these women must confront the knowledge and consequences of their spouses' infidelity (Muecke, 2001; Pradubmook, 1999; Songwathana, 2001).

Despite overwhelming demands, Thai women willingly continue to provide care for their husbands. The social and cultural expectations largely dictate women's caregiver role. Thai wives provide care for their husband because of a deeply rooted cultural sense of passion, love, moral obligation, belief in their social role and responsibility as a wife, and as a means to free themselves from suffering or blame from society (Phengjard, 2001; Songwathana, 2001). Women's inferior social status and these beliefs force them to put the needs of their families before their own well-being, thereby, placing their own health and medical needs as a low priority (Danziger, 1994; Songwathana, 2001).

The existing research in Thailand suggests that medical, social, and ethical issues surrounding HIV/AIDS profoundly impact the family caregiving for PLWAs. There have been few published studies in the experience of wives caring for their husbands living with HIV/AIDS in Thailand. This study is proposed as a way to examine this phenomenon in depth in order to add a much needed dimension to the Thai HIV/AIDS body of knowledge.

Statement of the Problem

The medical and nursing literature has extensively described HIV/AIDS family caregiving experiences in western countries, however, because of the differences in social and cultural contexts surrounding HIV/AIDS and Thai families, western knowledge cannot explain the HIV/AIDS family caregiving phenomenon in Thailand. Existing Thai research has focused on the characteristics of HIV affected families, caregivers' perceptions, readiness for caregiving, knowledge, skills, and abilities to care for PLWAs, and the family's needs while caring for the PLWAs (Janjarat, 1994; Kompayak, 1998; Pornsiripong, 1994; Somnalin, 1997; Songwathana & Manderson, 1998). However, while the impact of HIV/AIDS on the family is so severe, very few studies have examined the subjective experience of wives who are providing care for their husbands living with HIV/AIDS. Furthermore, much of existing research has been empirical, although the phenomenon of women caring for their husbands with HIV/AIDS is culturally bound and subjective. Since socio-cultural beliefs and values strongly influence how women construct their experience, it is critical to illuminate the issues and contexts surrounding HIV/AIDS caregiving.

Little is known about the impact of HIV/AIDS and caregiving on the experience of Thai women caring for their husbands with HIV/AIDS. Therefore, it is necessary to generate a theoretical understanding of female spouses' experience of caregiving for their HIV infected husbands in Thailand. The lack of information about this experience, from the perspective of the women caregivers, makes it difficult to conceptualize their situation and identify their psycho-social and health needs. Qualitative research is needed to uncover and understand the social meanings that influence Thai women caring for their husbands with HIV/AIDS and how HIV/AIDS caregiving affects their lives.

Research Aims

This study was designed to generate a substantive theory of HIV/AIDS caregiving in Thailand, and to further expand the body of knowledge in HIV/AIDS care, taking into account the social meanings, cultural beliefs, and values of female spouses caring for their husbands. The specific aims of this study were to:

1. describe the caregiving experiences from the perspective of Thai women caring for their husbands living with HIV/AIDS,
2. identify the processes and meanings related to providing care to husbands living with HIV/AIDS,
3. generate an initial grounded theory about wives' experiences of caring for their husbands living with HIV/AIDS in Thailand and identify:
    - (a) the social and cultural contexts of everyday life which influence Thai women's experiences of caregiving,
    - (b) the conditions that impact the caregiving experiences,
    - (c) the actions/interactions associated with caregiving experiences,
    - (d) the consequences of caregiving experience, and
    - (e) the social process of Thai women caring for their husbands living with HIV/AIDS

The development of an explanatory theory represents a significant step toward uncovering the social processes, concepts, and theoretical statements that explain the phenomenon of women caring for husbands living with HIV/AIDS in Thailand. This grounded theory study attempted to generate a theoretical explanation of HIV/AIDS caregiving focusing on the social processes, actions, and meanings of female spouse caregivers. It is hoped that this study will benefit health care practices and potentially improve health care providers' responsiveness to the problems facing female spouses.

Significance to Nursing

The Thai government began encouraging families to provide care for PLWAs at home. Thai nurses are now more focused on the psychological and sociological domain of illnesses and incorporate this knowledge in their care and services for individuals and families. One of the goals for Thai nursing practice is to develop effective and sensitive care interventions that will support PLWAs and their families, and to ultimately improve the entire family's health and well-being. Thus, it is crucial that nurse researchers understand the myriad aspects of HIV/AIDS caregiving from the perspective and experience of the family caregiver. By generating a conceptual theory of HIV/AIDS caregiving, this study serves as a framework to increase knowledge and understanding of the processes involved in the caregiving of PLWAs, so that problems can be identified and nursing strategies can be instituted.

CHAPTER 2

REVIEW OF THE LITERATURE

The proposed study was designed to understand Thai women's experience of caregiving for their husbands living with HIV/AIDS. This chapter provides background knowledge and contexts for an understanding of the phenomenon under study. Pertinent literature from both Western and Thai culture was reviewed to identify and describe many of the issues surrounding HIV/AIDS family caregiving and particularly women's experiences of caring for their husbands living with HIV/AIDS, thereby enriching data collection and analysis. The first section is a brief review of the social structure and worldview of Thai society. The next section reviews the literature on the social context of HIV/AIDS in Thailand. These first two sections offer an understanding of some of the social and cultural contexts in which women construct their meanings and experiences of caregiving. The third section reviews the literature regarding the HIV affected family. The forth section reviews the literature on HIV/AIDS family caregiving. The final section examines the current research related to the impact of HIV/AIDS on women done by Western and Thai researchers. The significant gaps in knowledge related to HIV/AIDS family caregiving in Thailand are identified in the last section.

Social Structure and Worldview of Thai Society

Cultural beliefs and norms largely determine much of the shared experiences in life. As such, Thai social structure and worldview influence Thai people's social and family relationships and attitudes toward illness and caregiving. The concepts of social hierarchy, gender role, sexuality, and Buddhist worldview in the Thai culture are elaborated.

The Thai societal system is chiefly hierarchical, thus social standings and responsibilities are specifically ranked based on social status, seniority, wealth, and power (Klausner, 1997; Suvanajata, 1976). Most of the social hierarchy is expressed through a superordinate-subordinate relationship (Podhisita, 1998). For example, traditionally, a husband is a leader, supporter, and protector of his wife, which gives him a culturally sanctioned right to demand that the wife be subordinate to him, thus a wife is expected to respect, comply, obey, and honor her husband (Boonmongkol, 1998; Suphametaporn, 1999).

The Thai people openly acknowledge the differences between social statuses and behave according to their requisite social position; and duties and responsibilities of each family member are well defined. For example, a wife is responsible for meeting her husband's and children's needs, rearing the children, and doing housework and maintaining the household. A "good wife" is a selfless, nurturing woman of refined manner, who is devoted to her husband and ready to sacrifice herself for the well-being and good of her family (Komin, 1998). It is well established that Thai wives provide care for their HIV infected husbands partly because of their social role and responsibilities (Pradubmook, 1999; Songwathana, 2001).

In addition to social status, gender roles are also socially constructed and clearly defined in Thai society. Women are always subordinate to men (Bandhumedha, 1998). A "good women" must be passive, quiet, obedient, and patient in accordance with her lower gender role. As a result of their perception, Thai women are hesitant to question their husbands about their extramarital activities. This cultural belief substantially increases the wife's risk of contracting HIV/AIDS form her husband (Archawanijkul, 1994).

Thai people's worldview regarding sexuality is based on a gender specific double standard. Generally, men have much more sexual freedom than women. Pre-marital and extra-marital sexual activities are accepted as part of male identity whereas Thai women are expected to be the faithful consort. Men may patronize prostitutes and be unfaithful after marriage. Thai men are the decision-makers regarding sexual relations. Many women cannot negotiate or refuse to have sexual relation with their husbands (Boonmongkol, 1998). Boonmongkol (1998) found that Thai women are powerless in negotiating condom use to protect themselves from HIV infection due to the perceived risk to their marital relationship, social and economic status.

Another important factor is the Buddhist worldview that teaches that life is part of nature, and therefore, no one can escape the "natural laws" such as suffering, sickness, and death (Klausner, 1997). Thai people's view of health and illness is influenced by Buddhist beliefs that things and events are beyond individual control and that nothing can be done to prevent or escape them. Consequently, Thai people are more likely to accept illness or unpleasant experiences as the product of their own "fate" (Podhisita, 1998).

According to Buddhism, one's life is limited by karma (a store of rewards and punishments), which determines life events that must be enjoyed or endured. Although much of the karma is inherited from a previous birth, the individual can positively or negatively influence that karma by doing good things or earning merit, and determine the character of this present life as well as the next life. Consistent with this Buddhist belief, one increases merit by caring for a sick person or offering kindness to others. These meritorious acts can purportedly ensure a prosperous rebirth as well as enhancing the possibility of improving one's position in one's current life (Tambiah, 1970). Thus, for Thai women, caring for an ill husband can increase merit and possibly result in positive karma (Songwathana, 2001). In addition, the act of selfless caregiving may not only decrease her future suffering but may also increase the possibility of someone caring for her when she becomes sick and dying of AIDS (Ruangjiratain, 2002).

Thai cultural norms and religious beliefs cultivate a sense of obligation to care for family members when they become ill and are unable to look after themselves. Current research findings show that a sense of duty and obligation are factors that influence the family's decision to give care to PLWAs (Muecke, 2001; Phengjard, 2001; Songwathana, 2001).

Social Context of HIV/AIDS in Thailand

The socially constructed meaning of AIDS greatly affects how Thai people perceive and respond to the disease and now they respond to those living with HIV/AIDS (Songwathana & Manderson, 1998). Discrimination and rejection against PLWAs and their family are common in Thai society. In the early period of the AIDS epidemic in Thailand, the stigma of AIDS was repeatedly reinforced through the AIDS prevention campaigns, that included the horrific pictures of terminally ill patient with the message that AIDS is incurable, deadly, and highly contagious, yet these campaigns did not include information about how to avoid infection and led to misperceptions and misunderstanding about HIV/AIDS. This dramatic and biased media campaign provoked extreme fear of the disease (Lyttleton, 1996). The literature reveals that the Thai people share a widespread fear and feelings of disdain bordering on disgust toward PLWAs and their family. Due to the strength of these negative perceptions by families and Thai communities, many PLWAs describe that they are more afraid of rejection than death (Limanonda & Nokyoongthong, 1995).

Furthermore, Thai PLWAs are regarded as "bad people" and believed to deserve the consequences of their immoral behaviors, such as injecting drug use, prostitution, and promiscuity (Sangchart, 1997). AIDS is also viewed as a disease of karma, sinfulness, immorality, hopelessness, and suffering. Death from AIDS is viewed as a "bad death" because it is premature and involves prolong suffering and disfigurement (Peeraya, 1997; Songwathana & Manderson, 1998).

In Western society, stigma of AIDS is primarily related to the prejudice against homosexuality (Alonzo & Reynolds, 1995). In Thai culture, the degree of stigmatization is determined by how the PLWAs contracted AIDS. PLWAs who become infected through socially unacceptable behaviors such as homosexuality, IV drug use, promiscuous sex, or prostitution, are more stigmatized than those who are innocent victims of AIDS. Thus, housewives, children, and blood recipients are not as negatively stigmatized (Songwathana & Manderson, 1998, 2001).

Family members of PLWAs may also experience stigmatization. This stigmatization may be in the form of discrimination, rejection, harassment, and threats to lose one's housing and employment (Powell-Cope & Brown, 1992). A study in Thai rural areas shows that most community members do not offer assistance or support for families living with HIV/AIDS (Singhanetra-Renard, Chongsatitmun, & Wibulsawasdi, 1996). Moreover, family members frequently receive negative reactions from the community even after the patient died. In fact, many people will not attend the funeral of a person who has died of AIDS (Limanonda & Nokyoongthong, 1995).

Although the public is currently encouraged to have more sympathy toward PLWAs, the negative perceptions about AIDS, discrimination and rejection against PLWAs and their family continues in Thai society.

HIV Affected Family

Knowledge generated from Western countries provides a clear picture of the impact of HIV/AIDS on families (Bor, Elford, Hart, & Sherr, 1993; Brown & Powell-Cope, 1993). The issues of social stigma (Bunting, 1996b; McRae, 1991; Poindexter & Linsk, 1999), isolation and secrecy (Powell-Cope & Brown, 1992), stress and coping (Brown, McDaniel, & Birx, 1995; Brown, 1993; Folkman, 1997; Folkman, Chesney, & Christopher-Richards, 1994), social supports (Turner & Catania, 1997), communication and disclosure (Powell-Cope & Brown, 1992), response to illness and changing structure and roles in families (Bor et al., 1993; Phillips & Thomas, 1996), and caregiver stress and burden (Brown & Powell-Cope, 1991; Bunting, 1996a; Folkman, Chesney, Cooke, Boccellari, & Collette, 1994; Reynolds & Alonzo, 1998) are broadly researched topics in Western society. Yet only a few systematic research studies have analyzed how HIV/AIDS affects the family. As of this writing, some Thai research has sought to describe the impact of HIV of HIV/AIDS on Thai families. However, increasingly, this area has been described in the Thai literature. The current literature provides some information about Thai families affected by HIV/AIDS.

Empirical evidence suggests that when both husband and wife are infected, the husband often dies first, leaving the woman to take care of the children and/or elderly parents although they have very few resources remaining (Im-em & Phuongsaichai, 1999; Manopaiboon et al., 1997; Songwathana, 2001). However, there are also families whose wives were infected from previous partners or from prostitution who then transmitted HIV to their current husbands (Kongsuriyanavin, 1997; Treemanka, 1996).

Some studies reported that marital and family relationships are affected by HIV/AIDS. Couples who have a positive relationship before HIV are more likely to stay together after the diagnosis, in spite of the realization that their spouses brought the infection to them. These couples are frequently better adjusted to their illness than the couples who do not have good relationships (Kongsuriyanavin, 1997). However, some couples separate once one or both are diagnosed as HIV positive. In these cases, the HIV infected person is found to turn to their family of origin to care for them. Often, single PLWAs rely on their elderly parents for support and care (Kuroprakornpong & Chaichana, 1996).

Generally, PLWAs keep their HIV status secret from family, friends, coworkers, and community. Most married PLWAs disclose their HIV status only to their spouse (Pradubmook, 1999). Most couples decide to conceal their HIV status to protect their family from discrimination and rejection, unless they need others' help, or they think a person who was told about the diagnosis will not have negative reactions and discriminate against them (Phengjard, 2001).

Too many PLWAs are abandoned by their family because of the extreme fear of contagion, loss of their family's reputation, and the discrimination by others. However, fro some Thai families, their sense of obligation to provide care, affection, safety, and security to family members, overcome their fear of HIV/AIDS. Their sense of duty often inspires them to care for the PLWAs with understanding, sympathy, and forgiveness (Phengjard, 2001; Ruangjiratain, 2002; Songwathana & Manderson, 1998).

Because of the high level of HIV/AIDS stigmatization in Thai society, these families are forced to live in secrecy. The family members experience strong feelings of embarrassment, shame, and fear of discrimination, rejection, and threats (Phengjard, 2001; Thampanichawat, 1999). As a result, many PLWAs and their families experience social isolation, loneliness, and lack of social support from the community (Ruangjiratain, 2002).

The financial burden of HIV/AIDS is one of the leading problems in Thailand (Chunhapran, Tanasil, & Tato, 1992; Im-em & Phuongsaichai, 1999; Janjarat, 1994; Ruangjiratain, 2002; Sangchart, 1997; Treemanka, 1996). HIV/AIDS care is extremely expensive. The cost of medical care, loss of family income, and caregiving expenses are just a few of the causes of financial struggling. PLWAs are frequently hospitalized with exacerbations of the disease in addition to very costly medicines and special care. As such, families are faced with significantly higher financial problems than other Thai families. Clearly, the impact of HIV/AIDS on the families will vary, depending on the socio-cultural and demographic context, the economic status of the family, the commitment to the PLWA, and the role of the HIV infected person (Danziger, 1994).

HIV/AIDS Family Caregiving

Caregiving is defined as a process of taking responsibility for, and providing for, the needs of another, including physical, emotional, social, spiritual and other needs (Bunting, 1992). It can also include maintaining the care receiver's environment. Caregivers may include formal or professional caregivers, and informal caregivers or those persons who have a strong commitment to the welfare of another, such as a family member (Bor et al., 1993).

Caregiving is often stressful and can be overwhelming for families caring for their loved one with HIV/AIDS. The degree of strain can be so great that caregivers report severe emotional and physical burnout from caregiving (Brown, 1993; Flaskerud & Tabora, 1998; Turner & Catania, 1997). Much of the cause of caregiving stress is related to the actual duties of caregiving (Pearlin, Aneshensel, & LeBlanc, 1997). For many families, the burden is composed of the physical challenges of caregiving (Brown, 1993) coupled with psychological and emotional feelings of hopelessness (Brown, 1993; Flaskerud & Tabora, 1998; Turner & Catania, 1997). Caregiving demands and tasks performed vary depending upon the illness trajectory and phase of caregiving. As the illness progresses, the role of the caregiver intensifies due to the greater demand of caregiving (Brown, 1997). Brown and Powell-Cope (1991) noted that many family caregivers were all to frequently struggling with feelings that they were "manage by the illness" and feeling the futility of never being able to do enough.

At the present time, research on the phenomenon of Thai family caregiving is in the beginning stages. However, the existing research of HIV affected families in Thailand confirm that medical, social, and ethical issues surrounding HIV/AIDS profoundly impacts the family even more than the physical and financial burden. The increasing complex demands of care, as well as the extended and uncertain illness trajectory, challenge the family who are caring for loved one living with HIV/AIDS (Janjarat, 1994; Nilmanat, 1995).

Much of the literature reflects that families must cope with the social stigma, and also the heavy financial burden (Im-em & Phuongsaichai, 1999; Jaruwat, 1997; Phengjard, 2001; Ruangjiratain, 2001; Songwathana & Mandreson, 1998). Other stressors associated with caregiving practices include lack of knowledge or education and skill regarding caregiving, lack of knowledge to protect themselves from infection, lack of caregiving support, and limited outside care resources (Chunhapran et al., 1992; Janjarat, 1994; Phengjard, 2001).

Janjarat (1994) interviewed seven families caring for PLWAs in Thailand to examine the impact of HIV/AIDS on families and their caring practice. They found that HIV/AIDS affects families socially, psychologically, and financially. Two of the more difficult struggles are the expected premature death of their loved ones and the heavy burden of AIDS care. These families expressed needs for financial, instrumental (caregiving supplies), and emotional support throughout the patients' remaining lifespan. For the families who have children, childcare becomes a major concern when the PLWAs are terminally ill or hospitalized. Furthermore, this study reflected that many family members used inappropriate or unsafe care practices as a function of lack of training and support.

Chunhapran and colleagues (1992) examined 60 caregivers from metropolitan Bangkok caregivers' needs and the problems in caring for an HIV infected person. The study results suggest that family caregivers need specific support in the form of medical supplies (e.g. antiseptic, wound dressing kit), caregiving assistance, knowledge about HIV disease, and financial support from public funds and social welfare. Other needs identified were emotional supports from people and agencies such as religious institutions, and counselors whom they can trust. Many caregivers reported that they want information about resource agencies e.g., anonymous HIV clinics, hotlines, HIV care centers in the community, and funding agencies. Caregivers also wanted more hospital beds in addition to prompt admission to the hospital when the PLWAS becomes seriously ill. The study substantiated other research in that the specific problems of caring for PLWAs were lack of caregiving knowledge, fear of contagious, financial burden, physical and emotional burnout, prejudice, marital problems, deteriorated health, and difficulty finding hospital care for PLWAs.

Although the existing research provides initial knowledge about characteristics of AIDS caregiving, the impacts of HIV/AIDS on families, and caregiving practices and needs, less is known about the experience of family caregiving and its meanings. To date, only one study specifically examines the family caregiving experience of Thai families.

This phenomenological study conducted by Phengjard (2001) described the experience of family caregiving for PLWAs at home. According to these findings, Thai families struggle with the stigma of AIDS and the rejection associated with HIV/AIDS caregiving, financial limitations, insufficient resources, and lack of caregiving support. The pain of being shunned by outside friends and neighbors is so great that these families attempt to minimize social contact, revise the truth, hide evidence of caregiving, and give few clues as to the reality of their situation. The components of HIV/AIDS caregiving in Thailand include shielding and protecting the PLWAs from community rejection, giving the PLWAs emotional support, providing physical care, and searching for health care. While Phengjard (2001) painted a clear picture of HIV/AIDS family caregiving in Thailand, the study does not identify the social processes that explain the family caregiving phenomena from the wife's perspective or to develop the theoretical constructs in relation to this experience.

However, Phengjard (2001) does provide important insight into the perceived meanings of family caregiving of PLWAs. As such, family caregiving encompasses care by a person who is family member who loves the care receiver. It symbolizes the sense of love that family members have for each other, and represents the family as a functioning unit with the objective of caring, comforting, and protecting its vulnerable members. For the person who receives care, family caregiving also means encouragement.

Although this study examined the meanings and experience of caregiving, the data reflect the perspective of multiple groups of caregiver, such as parents, spouses, siblings, and friends. It is expected that the experience and meanings defined by female spouse caregivers may differ from the more general and broad based sample from Phengjard's study. In response to this research need, the proposed study will seek to analyze the female spouse caregiving experiences with the goal of describing this specific population of HIV/AIDS family caregiver.

HIV/AIDS Caregivers

Much of the literature on HIV/AIDS family caregiving in the US is drawn from the male homosexual community and suggests that the majority of caregivers in the United States are young adult males (Brown, 1994; Turner, Catania, & Gagnon, 1994). Because the HIV epidemic in Thailand occurs in both heterosexual and drug use communities, the characteristics of Thai caregivers are different from American caregivers. In Thai culture, wives, mothers, and sisters usually take on the caregiving for their family member(s) living with HIV/AIDS. There are only a small number of fathers or husbands who provide care for PLWAs (Janjarat, 1994; Jaruwat, 1997; Phengjard, 2001; Somnalin, 1997). Empirical evidence suggests if the PLWAs are married, their spouses are the primary caregivers. In contrast, single or separated/divorced PLWAs are more likely to be care for by their parents, siblings, or relatives (Jaruwat, 1997; Singhanetra-Renard et al., 1996).

Several other studies explored the impact of AIDS caregiving. The negative effects of HIV/AIDS caregiving are widely documented in the western literature (Flaskerud & Tabora, 1998; Wight, LeBlanc, & Aneshensel, 1998) and reflect that family caregiver's health status may be negatively affected by the demand of physical care. Fatigue, sleep disruption, poor health, and frequent illness, are all problems caregiver must overcome (Folkman, et al., 1994). Stress, uncertainty, loss and grief, and burden comprise the psychological impact of caregiving (Brown, 1993; Brown, McDaniel, & Birx, 1995; Brown & Powell-Cope, 1991).

In Thailand, little research has focused on the effects of HIV/AIDS caregiving on the physical and psychological health of family caregivers. However, empirical information suggests that family caregivers experience much greater physical exhaustion or fatigue (Phengjard, 1998; Ruangjiratain, 2002). In particular, older caregivers can be adversely affected and other existing health problems are often exacerbated. Moreover, caregivers' psychological health can be affected due to feelings of overload, loss, grief, and fear of contamination (Im-em & Phuongsaichai, 1999; Phengjard, 2001; Ruangjiratain, 2002; Singhanetra-Renard et al., 1996).

Caregiving Tasks

Caregiving tasks are determined by the PLWA's stage of HIV disease. Western studies have identified the primary caregiving tasks as companionship, assistance with activities of daily living, and nursing care such as monitoring, medication administration, and cleaning wounds (Folkman, Chesney, & Christopher-Richards, 1994; Ward & Brown, 1994). Other tasks include interacting with the health care system, and insurance providers, and assisting patients with personal business (Brown & Stetz, 1999). Caregiving tasks usually are more intensive when the disease progresses to the advanced stage of the illness, or the PLWA develops cognitive impairment and dementia. Caregivers also provide emotional support and help the PLWA copes with the psychological stressors associated with the illness, including social stigma and discrimination (Danziger, 1994; Phengjard, 2001; Powell-Cope & Brown, 1992; Ruangjiratain, 2002).

The majority of western research on HIV/AIDS caregiving examined the experience of caregivers who were caring for a significantly disabled and debilitated HIV/AIDS patient. Brown and Stetz (1999) described HIV/AIDS and cancer caregiving in their qualitative study. The caregiving processes identified in this study include managing the illness, struggling with the health care system, managing the home environment, learning one' own strength, personal suffering, responding to family issues, and facing and preparing for dying. The results reflect that caregiving involves a wide range of activities that shifted from caring for the ill person to supporting someone dying.

Again, there is limited information about the task of HIV/AIDS caregiving in Thailand. Existing databases indicate that Thai families focus on hands-on care that reflect traditional Thai caregiving, and are less likely to report using advanced caring skills (Phengjard, 2001). It is also found that caregivers have limited knowledge about HIV disease and caregiving of PLWAs (Janjarat, 1994). Findings from Thai studies suggest that Thai families provide care in two areas: health and emotional care. Health care aims at meeting physical health needs such as managing symptoms, administering medication, meeting activities of daily living, and preventing contamination. Emotional care involves accepting the patient's emotional irritation, providing comfort, and giving encouragement to the PLWAs (Janjarat, 1994; Jaruwat, 1997). Another study suggests other important tasks of caregiving include searching for health care in the form of seeking and making decisions about the treatments for PLWAs (Phengjard, 2001). Findings suggested that Thai families are more focused on the present situation rather than future caregiving tasks, thus their caregiving is often improvised as new situations arise.

To summarize the basic research position at this time, Thai family caregivers have several serious deficits regarding caring for PLWAs. First, they lack information and skill in safe and appropriate ways to provide direct, physical care. Secondly, these caregivers are often overwhelmed with the many layer of caregiving including the physical demands, emotional strain of caring for a PLWAs, social isolation and cultural stigma of HIV/AIDS, and also the heavy financial burden. Finally, many caregivers do not make advance plans ore anticipate future needs.

The Impact of HIV/AIDS on Women

Women in Thailand face special problems related to the HIV/AIDS crisis. These women are affected by the strain of caregiving, but more importantly, are particularly at risk of disease transmission. This section focused on women affected by HIV/AIDS both as HIV/AIDS caregivers and HIV infected persons.

Women as HIV/AIDS Caregivers

Generally, Thai women are the identified care providers for the families. This pattern holds for the care of PLWAs. Women in the family are almost always the persons who provide care for the family members who are sick and dying of AIDS (Muecke, 2001; Songwathana, 2001). Although many Thai women today are often the primary income sources for their families (Women of Thailand, 1995), they still carry the responsibility as caregivers.

It is common that Thai couples affected by HIV are both HIV positive. Out of the total newly infected people in the year 2000, approximately half are married couples (Thai Working Group on HIV/AIDS Projection, 2001). Empirical data indicates that if a husband becomes ill first, his wife will care for him. In contrast, if the wife is sick with AIDS before her husband, her parents, especially her mother, more likely to care for her. Should both the husband and wife become sick, the wife will become the primary care provider for both herself and her husband (Songwathana, 2001).

Research shows that the couple is more likely to maintain the marriage when both parties are HIV positive or when the husband only is HIV positive (Kongsuriyanavin, 1997). If the wife alone has HIV, her husband will most likely abandon her (Manopaiboon, et al., 1998.) This phenomenon is largely culturally bond in that women are encouraged to forgive and accept the situation even when the news of HIV infection reveals their partner's extra marital sexual activity. Because culture supports the sense of obligation to be a good woman and wife, women will submit to their husbands (Pradubmook, 1999). In contrast, marriages are more likely to break down if it is wife who is infected with HIV, because it is assumed that she has been unfaithful to her husband (Kongsuriyanavin, 1997; Songwathana, 2001; Thampanichawat, 1999).

Songwathana (2001) found that cultural obligation, religious belief are part of the reason Thai wives provide care for their husbands. Women provide care to perform their social role and responsibility as a wife, to fulfill their moral obligation, and to free themselves from suffering or blame from their society. Other components are a sense of passion, deep love, for their spouse and families, and the emotional bonds (Phengjard, 2001).

As it is true in the U.S., Thai men place a higher burden on their spouse if she is also HIV positive. These women often fear for their own health as they watch their husband's decline. Not only is it hard to watch a loved on decline, these women also begin to see what is in store for them as the illness advances. HIV positive caregivers are physically vulnerable as their own disease progresses (Folkman, Chesney, & Christopher-Richards, 1994). In particular, HIV positive pregnant women struggle with the knowledge that their new baby may be HIV positive in addition to the challenges of their own and their husbands' health (Thampanichawat, 1999). Treemanka (1996) studied coping processes of HIV infected women in northern Thailand, and found that most women must accept their husbands' illness at the same time they have to accept their own illness. In addition, if the husband is dying, the loss of labor and income creates a tremendous financial burden on women both as caregivers and as survivors in assuming more of the financial responsibilities. Another study found that HIV infected women in rural areas are less likely to actively seek health care services and treatments for themselves because family resources were exhausted by their deceased husbands' illness (Im-em & Phuongsaichai, 1999).

Although most of the western literature regarding HIV caregiving has focused on homosexual partners, some work has been done on women caregivers in the U.S. There is a growing literature addressing the challenges of female caregivers (Bunting, 2001; Flaskerud & Tabora, 1998; Hackl, Somlai, Kelly, & Kalichman, 1997; Tolliver, 2001; Wight et al., 1998). Besides being a caregiver, some American women are also suffering from HIV/AIDS. These women reported that their families expect them to remain in the role as primary child and family caregiver. Chung and Magraw (1992) suggested that much of the women's stress is related to the strong emotional attachment and the social expectation on women to be nurturing, loving caregivers. As such, women struggle with the heavy caregiving responsibilities while also suffering the grief and loss from their own illness.

In Thailand, women tend to neglect their own health problems and needs because they view themselves as a lower priority in relation to the needs of their families (Smeltzer, 1992; Songwathana, 2001). The inferior socio-economic status and these cultural values prevent women from seeking medical care early and properly responding to their own health's needs. Furthermore, these women often experience low self-esteem and guilt because their illness prevents them from fulfilling their responsibilities and meeting their family's needs (Songwathana, 2001).

While there is little information about the health status and problems of female caregivers of PLWAs in Thailand, the US literature provides some relevant insights. Wight, LeBlance, and Aneshensel (1998) explored the impact of HIV/AIDS caregiving on the health of female caregivers such as mother, wife, sister, or friend. According to this study, wives reported poorer health and higher level of chronic symptomatology than other groups of female caregiver. In another study, health problems of low-income female caregivers of mother, wife or partner, daughter, sister and other relatives showed that these caregivers had significantly greater physical and mental health problems (Flaskerud & Tabora, 1998).

The unequal social and economic states of women may be a factor in the increased burden and distress in caregivers (Bruyn, 1992; Turner et al., 1994; Ward & Brown, 1994). In addition, more than 70% of female caregivers expressed a moderate amount of loneliness; felt that no one really wanted to talk about the PLWH or the disease; and offered scant help with care. These women reported consistent feeling of loss, anger, and isolation, captured with the social stigmatization of the disease.

Women as Persons Living With HIV/AIDS

Clinical evidence shows that women's risk of HIV infection is greater than men because transmission through heterosexual intercourse is more efficient from man to woman than woman to man (Sherr, 1996). Thus, women are biologically and socially more vulnerable to HIV infection. In Thailand, women generally contract HIV from heterosexual contact (Siriwasin et al., 1998). While the HIV prevalence is now lower in Thai commercial sex workers, the HIV prevalence among women is increasing, as measured by the steady increasing number of HIV positive pregnant women (UNAIDS/WHO Working Group on Global HIV/AIDS and STI Surveillance, 2000). Yet HIV positive pregnant women only represent a small proportion of the HIV positive women in the community. It can be assumed that many women do not feel the need to be tested, because they are not pregnant or symptomatic. However, in 2000, the percentage of husband to wife transmission accounts for approximately half of all new diagnosis. (Thai Working Group on HIV/AIDS Projection, 2001).

In addition to biological risk factors, Thai women are culturally and socially more vulnerable to HIV infection. A large number of Thai women are at greater risk of exposure due to their husbands' high risk behaviors such as IV drug use, multiple sexual partners, and frequent sexual activities with prostitutes (Kaewthep, 1999; Pradubmook, 1999; Thompson, 1999).

Married Thai women cannot protect themselves from HIV because the Thai culture dictates that women are intrinsically inferior to men and must passively submit to their husband's sexual demands (Boonmongkol, 2000). Other factors that influence women's heightened risk are the social double standard that tolerates male infidelity and high risk sexual behavior, the women's economic vulneralbilities and social inferiority in addition to the cultural stricture that forbids women from forcing their husbands to use condoms (Bruyn, 1992; Kaewthep, 1999; Thompson, 1999).

Furthermore, Thai women are passive in sexual relationships. They do not readily discuss sex, safe sex practices, sexually transmitted diseases, or their personal sexual desire and preference. Women must not question their husband's fidelity nor can they refuse to have sex. Should the women attempt to take an active role in their sexual relationship, they run the risk of separation, divorce, and economic and social poverty (Thompson, 1999).

At this time, most of the research on Thai women living with HIV/AIDS has been limited to pregnant women (Chaiprasit, 1994; Kongsuriyanavin, 1997; Manopaiboon et al., 1998; Thampanichawat, 1999). However, these women also experience many other challenges including: reproductive decisions, their children's health and care, multiple deaths of family members, changes in family and marital relationships, and role stress. In addition, women living with HIV/AIDS are still responsible for their immediate families and required to fulfill their multiple roles when the family is affected by HIV. They feel duty bond to care for their family even when very ill themselves (Songwathana, 2001; Songwathana & Manderson, 1998). Women's roles are determined by family needs at the time (Muecke, 2001). Often women assume the roles of wife, mother, worker, and caregiver, sick person, secret keeper, family leader and wage earner, as their husband is sick or dying. Most women fulfill these role responsibilities without sufficient family and social support. However, Thai women do gain some spiritual strength through their strong Buddhists religious beliefs that provides meaning to their lives. Thus, Buddhism provides a source of strength and comfort for them to gain acceptance of the fate and suffering of self, their family members, and children (Pradubmook, 1999; Sangchart, 1997).

Significant Gaps in Knowledge in Thailand

It is quite apparent that only minimal data exists on the caregiving experience and the impact HIV/AIDS caregiving practice have on women and their families. More importantly, very few Thai studies have examined the effects of HIV/AIDS on family caregiving in relationship to the entire illness trajectory. This illness trajectory appears to change according to the health of the PLWAs and often adds to the uncertainty and stress of caregiving.

Knowledge specific to different groups of HIV/AIDS caregiver, such as parents, spouses, same sex partners, and grandparents, is important in expanding the body of knowledge of HIV/AIDS caregiving. To date, specific information about a wife's experience of caregiving is not available. Although social and cultural beliefs/values about gender, social role, family obligation, marriage, and sexuality, directly influence Thai women's experience as caregivers and the perception of their caregiving, very few studies have systematically addressed them. Furthermore, very little data exist that describes the care tasks Thai families perform. This information is important to health care providers in order to assess the care needs of families. There is limited information about what contributes to the great commitment of family, especially the female spouse, to care for loved one living with HIV/AIDS, while others refuse. This study is proposed as a way to fill some of these research gaps.

More qualitative and descriptive research is needed to deepen the understanding of the experience of HIV/AIDS family caregiving from the caregiver's perspective. Without this information, effective HIV/AIDS care programs are not possible and family interventions to assist Thai families providing care to the PLWAs are limited. Women's experience of caregiving will increase the recognition of the value of women's work in Thai society and the need for support during family caregiving. This study will add to the existing body of knowledge and provides much needed insight information of this phenomenon.

CHAPTER 3

RESEARCH DESIGN AND METHODS

Grounded theory research method was selected for this research study to generate a theoretical explanation of female spouse's experiences of caregiving for her husband living with HIV/AIDS in Thailand. In this chapter, symbolic interactionism, a theoretical framework of grounded theory approach, will be described first. Next, an overview of grounded theory approach will follow and include the development of grounded theory, the method of grounded theory, the philosophical underpinnings, the analytic components and analytic process of grounded theory. The final section will focus on the justification of this method for the proposed study, in addition to the study sampling, setting, sample, recruitment procedure, data collection, data analysis, trustworthiness, and human subject protection.

Symbolic Interactionism

Symbolic interactionism is a theoretical construct that provides a means to study social life and behavior. Although symbolic interactionism originated in social psychology and sociology, a wide variety of scholars have adopted this theoretical perspective. The basic tenets and assumptions of symbolic interactionism will be presented, followed by a discussion of its use as a framework for grounded theory research.

Basic Tenets and Assumptions

According to Blumer (1969), the basic tenets of symbolic interactionism maintain that: (1) humans act toward things, such as other persons, physical objects, institutions, activities, ideas, and situations, on the basis of the meanings that humans assign to them; (2) meaning of such things arise out of social interaction that humans have with others; and (3) meaning is modified by each individual through an interpretative process.

The ability to generate meaning through interaction with others and to share meanings can be argued as a principle difference between humans and animals. Blumer (1969) emphasized the process of interaction in the creation of social and individual meanings and also asserted that meanings are central to explaining and accounting for human conduct. Therefore, social interactionism maintains the view that human behavior can be understood through the meanings such behavior holds for the individual.

Symbolic interactionism also describes how people develop their conception of self. Blumer concurred with Mead's (1934) assertion that people define themselves through social roles, expectations, and perspectives of self by society and its members. Mead (1934) conceptualized the "Self" as a construction of the interaction between one's self-conception (I) and the generalized, perceived view of what others think of him/herself (ME). The interaction of an "I" and "ME" is an ongoing process by which we come to understand and define our humanity. Thus, symbolic interactionism allows people to communicate, behave, and conceptualize oneself.

Mead (1934) believed that self, mind, and symbols develop simultaneously. Because humans have a mind, which is capable of reflecting on its own processes, the individual can therefore develop a self as both actor and object. By continually reflecting on ourselves as others see us, we are able to produce and display social symbols. Blumer proposed that social life is expressed through symbols and that symbols and language provides the mechanism for social construction of the mind and is critical to developing self-awareness. Moreover, Mead viewed a human's ability to learn and use symbols as the basis for human society because we live in a symbolic world as well as a physical world. Through language and symbol, humans communicate and affirm the shared meanings of the physical, cultural and social worlds.

Subsequently, we develop ways of acting on the basis of symbols we have learned from others and our beliefs about the importance of these meanings.

Lastly, another fundamental tenet of symbolic interactionism is that human beings engage in varied actions as they encounter others in everyday situations (Blumer, 1969). Based on this assumption, symbolic interactionists view human groups or society in term of action and acting individuals rather than the whole social system (Bowers, 1988). Thus, it is then the social structure of people that determines how people act toward each other.

Symbolic Interactionism as a Framework for Grounded Theory Method

Blumer (1969) emphasized the need for a special research methodology to capture the unpredictable and subjective aspects of the social construction of meanings and human interactions. Grounded theory grew from this need. The basic tenets of symbolic interactionism regarding human social interactions and processes were incorporated into the foundation of grounded theory method. Grounded theory offers a way to view a phenomenon as it is perceived and reported by individuals within their social interactions and to also observe how those interactions take on meaning. As such, grounded theory is an interpretive account of the phenomena from the perspective of the study participants.

For symbolic interactionists, the human actions/interactions must always be viewed in the specific social and historical contexts. Therefore, the methodological focus of symbolic interactionism is a direct investigation of the empirical world, that is, the world of everyday experience (Blumer, 1969). Congruent with the theoretical stance of symbolic interactionism, grounded theory describes human behavior as it takes place in the subjects' social and historical contexts and also in their naturalistic settings. It aims at developing a theory that is grounded in the empirical data derived from human's everyday experience in the social world

(Glaser & Strauss, 1967). It is through this process that a conceptually dense theory developed to capture variations in human social interaction as they occur around a central phenomenon.

Grounded Theory Approach

Grounded theory approach is a qualitative research method, which uses a systematic set of procedures to inductively generate an empirically based theory about the social phenomenon. Grounded theory can be "discovered, developed and provisionally verified through systematic data collection and analysis of data" (Strauss & Corbin, 1990, p. 23). Grounded theory researchers do not begin with an existing theory and validate it through theory testing, but rather start with the empirical data and then conceptualize and interpret the data to form a theoretical explanation of reality or theory.

The term "grounded theory" is used to designate both the research process of theory development and the theoretical product. Grounded theory method is designed primarily for theory development rather than description production regarding a phenomenon under study. The derived theory is then grounded in the data and illuminates human behavior and social world. The goal is to generate a theory that: 1) fits the data, 2) works, as it conceptually represents the core of what is going on, 3) is relevant to the studied phenomenon, and 4) is modifiable to the ever-changing world (Glaser, 1978). In grounded theory research, the processes of data collection and theory generation are simultaneous actions that are then directed and integrated by the emerging theory (Glaser, 1978).

The Development of Grounded Theory

Influenced by American pragmatism and symbolic interactionism, Barney Glaser and Anselm Strauss developed this method to derive theory from data in the early 1960s. They introduced this method in their book: *The Discovery of Grounded Theory: Strategies for Qualitative Research* (1967). Glaser and Strauss developed their framework in response to the common positivist practice of validating a priori theory in social inquiry. However, as the method of grounded theory grew and changed, Glaser and Strauss differed. Anselm Strauss began collaborating with Juliet Corbin (Strauss & Corbin, 1990) and presented a major reformulation of grounded theory in 1990. Their publication caused significant controversy between the two originators of grounded theory. Glaser disagreed with Strauss and Corbin's analytic procedures, which he believed force data through preconceived questions and frameworks. Glaser emphasized emergence of data and theory through the use of systematic comparison known as constant comparative analysis.

According to Kendall (1999), the major difference between Glaser's approach and Strauss's approach is in their approach to analysis; that is, a coding procedure called axial coding proposed by Strauss and Corbin (1990). Strauss and Corbin (1990) suggested the use of a paradigm model to help the researcher think systematically about the data and encourage the researcher to ask questions about the subcategories of data as they relate to each other, and thereby connecting the subcategories to a central idea or core category. This coding paradigm consists of six subcategories: conditions, phenomena, context, intervening conditions, actions/strategies, and consequences. Glaser (1992) disagreed with the paradigm model because he believed these codes were forced into a particular scheme rather than being driven by emergent conceptual interests that were grounded in data. Glaser claimed that Strauss and Corbin's method resulted in a full conceptual description of the social world with poor integration of theoretical explanations rather than a rich and complex theory that is grounded in the data. Strauss and Corbin's (1990) techniques were perceived as taking the researcher away from the data and move toward positivism (Robrecht, 1995). Although theoretical assumptions of symbolic interactionism are inherent to the grounded theory method, it does have underlying philosophical assumptions, which will be discussed next.

Philosophical Underpinnings of Grounded Theory Approach

Since its introduction by Glaser and Strauss in 1967, grounded theory has evolved in different directions based on the philosophical perspectives of its proponents. These differences lie in the basic ontological and epistemological assumptions. The original version of grounded theory emerged from the positivist assumptions of universality and objectivism. Glaser (1978, 1992) maintained that it was possible to create a realist ontology that was independent of, and was able to be observed objectively. Although the position later moved toward postpositivism, as is evident in Strauss and Corbin's 1990 and 1998 publications, the position remains entrenched in objective underpinning aiming towards unbiased observation and verification of external reality.

The realist ontology and objectivist epistemology of traditional grounded theory are frequently criticized. The ontological assumption of external reality (i.e., the world has a real existence outside of human experience) fails to recognize meanings, multiple social realities, and mutual creation of knowledge by the viewer and the viewed (Charmaz, 2000). For positivist grounded theorists, objectivism is possible. Thus, knowledge can be independent of the observers and methods used to discover it. They view themselves as external observers and can be distanced experts who are independent from the data and can accurately and objectively interpret and represent data. However, objectivism and rigid analytic strategies can limit the understandings of human's subjective experiences and their meaningful social worlds (Charmaz, 2000).

As a result, the recent criticism of traditional grounded theory, a constructivist approach was introduced by the new generation of grounded theorists. Charmaz (2000) proposed "researchers can use grounded theory methods to further their knowledge of subjective experience and to expand its representation while neither remaining external from it nor accepting objectivist assumptions and procedures" (p. 521). Constructivists claim that a grounded theory approach that emphasizes emergent and constructivist elements offer better interpretive understandings of the empirical world.

Relativist ontological and transactional/subjectivist epistemological assumptions lay the foundations for constructivist grounded theory approach. Constructivists reject the idea that truth can be universally and ultimately known and adopt the notion that truth is subjective and varying (Lincoln & Guba, 2000). Thus, social reality is in process because the specific circumstances and humans change over time. For constructivist grounded theory, the aim of inquiry is not to discover universal ultimate truth, but to seek to portray an image of multiple realities, which are both subjective and temporal. Based on the participants' meanings and actions, grounded theorists can thereby interpret how participants construct their realities. In addition, constructivists assume that the existence of mental, social, psychological and linguistic worlds allow humans and their social groups to create, re-create, and co-create. Therefore, knowledge cannot be viewed as distinct from ones' mental, social, psychological and linguistic worlds (Lincoln & Guba, 2000).

Furthermore, constructivist grounded theorists recognize that knowledge is derived from the mutual creation by the viewer and the viewed. Constructivists maintain that it is possible to interpret realities that are constructed and shared by the viewer and the viewed. Charmaz (2000) stated "a world made real in the words in the minds and through the words and actions of its members" (p. 523). Grounded theory is a product of interpretation of the constructed and shared reality between researchers and respondents rather than through an uncontaminated respondents' reality. Constructivists acknowledge the researcher's contribution to the respondents definition of realities and "how, when and why researchers portray these definition as real" (Charmaz, 2000, p. 523). The product of grounded theory inquiry is not objectified and does not seek to verify, predict, or generalize as is proposed by conventional grounded theory approach, but rather to provide a set of concepts and conditional statements to similar problem and situations (Charmaz, 2000).

The Method of Grounded Theory

Grounded theorist strive to generate theory that is grounded in data to explain the social phenomena under study. The goal of grounded theory inquiry is to discover a basic social process, which is then identified as the core category that best represents the problem or phenomena. The product of the inquiry is the *grounded theory,* which has been "derived from data systematically, gathered and analyzed through the research process of interrelated activities including data collection, analysis, and theory developing" (Strauss & Corbin, 1998, p. 12). Using grounded theory method, the derived theory will fit the data they represent, be able to explain the phenomena under study, and be relevant to the actual problem in the real world (Glaser, 1978).

The unique feature of a grounded theory method is in the analytic process of constant comparative analysis. Glaser and Strauss (1967) proposed the comparative analysis strategy to help generate, develop and relate concepts. The theoretical comparisons are made between incident and incident, concept and concept, concept and incident (Glaser, 1978), between different people in terms of their views, situation, actions, accounts and experiences, and between data from the same group collected at different times (Charmaz, 2000). Glaser (1978, 1992) emphasized the importance of constant comparative analysis. Theoretical comparisons not only facilitate objective thinking through an examination of a concept at its property and dimensional levels, but also direct theoretical samplings (Strauss & Corbin, 1998). In addition to the constant comparative analysis, grounded theory method contains other analytic components of naturalistic inquiry.

Grounded Theory Analytic Components

Grounded theory analytic components include: (1) theoretical sensitivity, (2) emergent design, (3) theoretical sampling, and (4) theoretical saturation. These components are critical to an understanding of grounded theory method.

Theoretical sensitivity. Theoretical sensitivity refers to the analytic activity of data comparison. The analyst enhances the theoretical sensitivity by discovering properties, dimensions, and relationships of the data by comparing data systematically and theoretically against each other (Strauss & Corbin, 1998). Another way to describe theoretical sensitivity is that of the ability to be "sensitive to thinking about data in theoretical terms" (Strauss, 1987, p. 21). Grounded theory requires the analyst to be open and sensitive to what is happening in the field and to what the data are saying. At the same time, it is necessary for the analyst to be aware of personal preconceived ideas or biases that can obscure the analyst's vision and limit sensitivity to meanings inherit in the data (Glaser, 1978; Strauss & Corbin, 1998). Studying in a western country for several years, this researcher is aware of the possible biases that arise from her experiences with western education. When studying women's experiences in caring for their husbands living with HIV/AIDS in Thailand, it is crucial to be aware of this background influence.

It can also be assumed that the analyst brings his/her personal/professional experiences and expertise to the research. The researcher's personal background as a Thai woman, wife, a person growing up in a Buddhist society, and a nurse, sensitizes her to the situation and experience of the Thai women she studies. For example, because the researcher is a Thai woman, she may perceive that caregiving of sick family members is not a choice, but a family's obligation; and women are expected to take a role of caregiver in the families. This personal and professional background may allow theoretical sensitivity in a way that enables the analyst to recognize the problems, issues, and meanings in the data (Strauss & Corbin, 1998).

Emergent design. Grounded theory seeks to explain how the social reality is constructed, multiplied, and is dependent on unpredictable interactions between the viewer and the viewed (Charmaz, 2000). Therefore, rather than being predetermined, grounded theory design must evolve as the inquiry proceeds based on the emerging insights, concepts, and theory grounded in the data (Lincoln & Guba, 1985). At the beginning of research, the investigation must be conducted in as open and as broad manner as possible; the investigation become more specific and focused as the research progresses. Emergent design indicates that data collection and analysis occur alternately throughout the research process and is influenced by what the analyst learns guides further data collection. Generating grounded theory is an evolving process where emerging theory is modifiable as new information about concepts emerges from the data (Strauss & Corbin, 1998).

Theoretical sampling. Theoretical sampling can be defined as "data gathering driven by concepts derived from the evolving theory and based on the concept of making comparisons" (Strauss & Corbin, 1998, p. 201). As such, the analyst does not determine in advance what and where to sample until specific categories emerge from earlier data analyses that indicate theoretical relevance as the analyst makes theoretical comparisons. The analyses and evolving theory thereby inform further data collection in terms of what and where the data should be collected (Glaser, 1978). Driven by what is learned, the analysts continue to sample incidents, events, people, or problems to discover variations among categories. In the study of women's experiences of caring for their husbands living with HIV/AIDS, if "social discrimination" is a category, varied in degree, type, actor and victim of discrimination, then the researcher might sample incidents of discrimination or people who experience discrimination along the lines of these properties and dimensions to maximize opportunities for comparison. Through the process of making comparisons, variations within the category of social discrimination and their relationships are identified based on the similarities and differences of their properties. It is this process of theoretical sampling that enables the analyst to differentiate categories, identify their variability, and develop theoretical density (Strauss & Corbin, 1998). In the early phase of data collection, theoretical sampling aims at discovery. As analysis proceeds, sampling becomes more focused toward developing, densifying, and saturating theoretical categories. Theoretical sampling ends when categories are saturated and integrated into the theory (Glaser, 1978).

Theoretical saturation. The analyst continues theoretical sampling until all categories reach theoretical saturation. Theoretical saturation occurs when: (1) the properties and dimensions of each category are fully developed and represent the variations of the phenomena under study; (2) the relationships between categories are validated; and (3) theoretical sampling and comparisons yield no new information regarding categories emerging from the analysis (Glaser, 1978; Strauss & Corbin, 1998). When all categories are as fully saturated, the theory is developed as fully as possible, and can adequately explain the phenomena under study. At that point, data collection and analysis are completed (Glaser, 1978).

Grounded Theory Analytic Processes

Grounded theory analysis requires a series of analytic strategies that aim to identify, refine, and relate the concepts and their relationships, and to integrate them into a theory. This study's analysis strategies were based on Strauss and Corbin's approach (1998). The first analytic strategy is that data collection and analysis occur simultaneously and alternately. The second analytic strategy consists of three types of coding: open, axial, and selective coding, whereby each code evolves from the analytic procedure of constant comparison. The third analytic strategy is the utilization of an analytical framework called conditional/ consequential matrix. Theoretical sampling is the fourth analytic strategy used throughout the analytic work. Memo writing and diagram drawing constitute the last analytic strategy.

Open coding: Microanalysis. The grounded theorist analyzes data, as they are collected and simultaneously begins the coding process. Coding requires conceptualizing or abstracting and categorizing data (Strauss, 1987). Initially, data are carefully examined and interpreted using line-by-line coding. This form of coding is termed as *microanalysis* (Strauss & Corbin, 1998) and is used in both open and axial coding. In microanalysis, the analyst engages in a conceptual mode of analysis by continually asking theoretical questions of who, when, where, what, how, and why, in order to make theoretical comparisons along the levels of properties and dimensions. These techniques not only allow the analyst to be sensitive in discovering properties and dimensions of the categories, relationships, and variations inherited in the data, but also help the analyst to direct theoretical sampling. Line-by-line analysis helps the analyst construct categories, discover the categories' properties, dimensions and relationships, while also incorporating the respondents' view and recognizing the analyst's own assumptions and biases (Charmaz, 2000; Strauss & Corbin, 1998).

In open coding, the analyst reduces data (incidents, events, happenings, actions/interactions) into pieces, or data bits, and explores their similarities and differences in terms of their properties (characteristics) and dimensions (range of characteristics). Analytic procedures include asking theoretical such as what is going on in the data, and by making comparisons to identify similarities and differences of their properties, and then conceptually group them into a "category". A category is defined as an abstract concept that represents and describes incidents, events, happenings, objects, actions/interactions or phenomena (Strauss & Corbin, 1998).

Axial coding. The emergent categories are then further developed under axial coding. Axial coding, particularly introduced by Strauss and Corbin (1990, 1998) is a way to systematically think about the relationships between categories and to begin to determine the most important features of the developing theory. This analytic procedure consists of sorting out data by making connections between categories and their subcategories using an analytic structure called the Paradigm (Strauss & Corbin, 1998). The Paradigm serves as an organizational scheme to help the analyst systematically links subcategories and identify the complex relationships in order to explain the phenomenon. The Paradigm's basic components are conditions, phenomenon, actions/interactions, and consequences (Strauss & Corbin, 1998).

In this process, the categories that emerge from open coding are related by assigning them as conditions (causal, intervening, and contextual), phenomenon, actions/interactions (strategic, routine), and/or consequences. As the analyst organizes the categories through the Paradigm, their relationships and salience emerge to make and validate relational statements (hypotheses) through theoretical comparisons of data incident to incident.

The processes of open and axial coding are not discrete or sequential, but proceed together. Categories and their properties and dimensions are developed at the same time the relationships are sorted out. Strauss and Corbin (1990, 1998) stressed that during open and axial coding, microanalysis (careful, line-by-line examination of the data) is performed using comparative analysis to identify a range of potential meanings hidden in the data, uncover concepts, generate categories, discover their properties, dimensions as well as their relationships.

Selective coding. The final step of analysis is selective coding which refers to the process of integrating and refining the categories to form the theory. Selective coding procedures include: (1) affirming the core category or central theme; (2) checking for internal consistency and logic; and (3) filling in poorly developed categories (Strauss & Corbin, 1998). In the integration stage, the analyst writes a story line and draws an integrative diagram, to further sort and review memos that related to each of the categories and their connections. This process then seeks affirmation of the selected core category, integration of the other categories, and finally refines the theory. Once the core category is selected, the categories can be organized around the core category based on the Paradigm (Strauss & Corbin, 1990). The analyst engages in final integration process to generate a theoretical outline through sorting memos and drawing diagrams. A theoretical outline is to write a theoretical explanation that describes the relationship between the major concepts of the theory and to the core category. These theoretical statements are validated against the data for consistency and logical development. The theory is then further refined by filling gaps in underdeveloped concepts to achieve density and specificity, and to eliminate concepts that do not fit.

Conditional matrix. In addition to coding procedures, Strauss and Corbin (1998) proposed an analytical tool called conditional/ consequential matrix to aid the analytic work by locating a phenomenon in the micro/macro context. This involves conceptualizing the connection of conditions, actions/interactions, and consequences within the events. The matrix consists of a series of concentric and interconnected circles with arrows. Its center stands for the phenomenon under study surrounded by evolving actions/interactions; the areas between circles represent different structural contexts such as conditions/consequences in which the actions/interactions occur-- from more micro (e.g. individual, family, group) to the macro (e.g. organization, community, nation). The area between the circles represent the intersection of the conditions/consequences (structure) and the chain of events (process) is indicated using arrows. By systematically following the chain of events, the analyst can trace the connection between the conditions and consequences associated with actions/interactions and the influences of the consequences (as new conditions) on subsequent actions/ interactions. If these connections emerge from the data and seem important or useful in explaining a phenomenon, it deserves further investigation. By thinking in terms of the matrix, the analyst can see the complex nature of the events and their connections, making decisions about theoretical sampling (Strauss & Corbin, 1998).

Memo writing. Memo writing is an essential analytic procedure of grounded theory and is consistently used through out the analytic work from open coding to the final writing of the theory. Writing memos force the analyst to review the data conceptually. Theoretical memoing is a method of recording analytical and conceptual ideas, which occur during data collection and coding, in order to keep track of the analytic process that will include theoretical thinking, conceptual decisions, and the development of theory (Strauss, 1987; Strauss & Corbin, 1998). By on-going memo writing, the analyst: "(1) grapples with ideas about the data; (2) sets an analytic course; (3) refines categories; (4) defines the relationships among various categories; and (5) gains a sense of confidence and competence in an ability to analyze data" (Charmaz, 2000, pp. 517-518).

Research Design

This study was designed to describe the experience of Thai women caring for their husbands living with HIV/AIDS. Grounded theory, as described by Strauss and Corbin (1998), was selected as the method for this study. The research design was emergent and was comprised of the analytic components of theoretical sampling, intensive interviewing, and inductive analysis using the constant comparative method (Strauss & Corbin, 1998). These components were performed concurrently throughout the research process until theoretical saturation was achieved and the grounded theory was generated. The grounded theory method enabled the researcher to generate a substantive theory about the experience of Thai women caring for their husbands living with HIV/AIDS.

Justification for Use of Grounded Theory

Previous research studies offered some data regarding the experiences of Thai caregivers and described some of their difficulties in caring for HIV infected persons, but none of them examined the caregiving experience specifically from the female spouse's perspective. The female spouse caregivers' subjective experience of her life and how their world evolves caring for their husbands living with HIV/AIDS is critical information if effective programs are to be developed to meet their needs. Because HIV/AIDS caregiving phenomenon has not been well studied in Thailand, grounded theory was an appropriate method to add insight and better understanding of HIV/AIDS caregiving, especially from female spouse caregiver's point of view. Additionally, the processes and changes in the lives of Thai women caring for their husbands living with HIV/AIDS have not been adequately described. Thus, grounded theory method was selected because it enabled the researcher to develop an explanatory theory of the phenomena and to identify the social processes of Thai women caregiving experiences.

In this study, constructivist assumptions underlied the grounded theory approach (Charmaz, 2000). The reasons that constructivist grounded theory approach was adopted in this study was threefold. First, the purpose of the study was to explore the women's subjective experiences from their own perspective. Constructivist grounded theory enables a reflexive investigation to gain knowledge about the personal experiences from the standpoint of the women who live it. Second, constructivist grounded theorists acknowledge the role of researcher in the inquiry in that the researcher interacts with the respondents in the field, ask questions about the data, shapes data collection, and redirects the analysis. The researcher's perspectives and meanings were constructed by social status, as a professional nurse and as a scholar educated in a western institution and residing in western culture. Because these constructions are unconsciously presented in the research process, the emerging theory arising out of grounded theory reflects the interpretation and the meanings of both the research participants as well as the researcher.

Third, the pilot interview of a Thai woman who was caring for an HIV infected husband, revealed that her experiences and stories were strongly associated with the social contexts of Thai society, including Buddhist beliefs, gender role, and social stigma surrounding AIDS in Thai society that influence how women experience, interpret and respond to their situation. For example, in Thai culture, women are viewed as nurturers and family caretakers (Muecke, 2001) and the experiences and views of sufferings and premature death are shaped by the religious context of Buddhism (Songwathana, 2001). As a result, Thai women tend to view HIV infection, suffering, and premature death as results of their karma. The stigma associated with AIDS is created and perceived through social and cultural context and Thai society views AIDS as a prostitute's disease and is a punishment for individual's deviant behaviors. Thus, Thai culture attests that the PLWA deserves to die as a result of his/her own action (Danziger, 1994; Songwathana & Manderson, 1998). Because much of this phenomenon is context-bond, the constructivist perspective was adopted to guide the grounded theory approach. Constructivist grounded theory allowed the researcher to study the participants in their natural settings and portray the contexts as part of the basis for interpreting the meanings of the participants' stories.

Sampling

In this study, both purposive and theoretical sampling techniques were used. Consistent with the methodological assumptions of grounded theory, the sampling began with purposive sampling. Participants were chosen initially to reflect the fullness of experience. Subsequently, theoretical sampling was used to fill gaps in the theoretical understanding of the data.

The final sample size of 20 was determined by theoretical consideration. The researcher continued the theoretical sampling until every category in the generated theory reached theoretical saturation. According to Strauss and Corbin (Strauss & Corbin, 1998), sampling may be terminated when the newly sampled units yield no new information regarding categories, the properties and dimensions of each category are fully developed and when the variations of the phenomena under study, and the relationships between categories are validated.

Setting

A convenience sample was recruited from the HIV/AIDS clinic at one of the largest public university hospitals in Bangkok, Thailand. Due to the large number of PLWAs who receive health care services at this clinic, there was a large population of married men living with HIV/AIDS who were being cared for by their spouses. This health care facility was the leader in advanced HIV/AIDS care and treatment in the country. The majority of the HIV/AIDS patients served in the clinic were from the metropolitan Bangkok, however, the clinic also served HIV/AIDS patients from all over the country who seek the best care available. Although the clinic was open Monday through Friday, the majority of HIV/AIDS patients were scheduled for their visits on Tuesday. Thus, the researcher visited the clinic every Tuesday in order to access the large number of participants needing to be recruited. The researcher also elected to visit on other days if additional participants were needed.

Sample

Because the purpose of the study was to learn about the caregiving experience of women caring for their husbands living with HIV/AIDS, female spouses who were the primary caregiver of PLWAs were recruited as participants of this study. For the purpose of this study, the PLWA was a man who identified himself as HIV positive and was cared for by his spouse. The primary caregiver of the PLWA referred to a woman who identified herself as most involved in providing care to the PLWA. In this study, the care provided by the caregiver included physical care (i.e. assist in daily living activities, hand-on care), emotional care (i.e. giving support and encouragement), HIV/AIDS symptoms management, care coordination and decision making, acquirement of services, and management of household/personal business.

The inclusion criteria included:

(1) participant was 18 years of age or older

(2) participant and her husband lived in the same household

(3) by self-report, participant was the primary caregiver of her husband who was living with HIV/AIDS

(4) participant was able to provide informed consent and was willing to participate

(5) participant was able to articulate her experience and participate in the interview

Participants who had severe neurological impairment, psychosis, or were hospitalized during the study were excluded due to concerns regarding participant burden and/or potential inadequacy of the data.

Recruitment Procedure

Recruitment began after the researcher received written permission from the participating clinic and the approval from both Oregon Health & Science University Institutional Review Board and the university's Ethical Committee on Human Rights Related to Research Involving Human Subjects.

A clinic staff member was selected and trained by the researcher to distribute announcement flyers (see Appendix A) and explained the study to potential participants. The designated clinic staff distributed the flyers describing the study to women who were receiving care at the clinic or women who were accompanying their husbands to the clinic. To protect woman's confidentiality, the flyer was given to the woman when she was alone in a designated private room. The staff asked the woman to read the flyer, however, a few of the women were illiterate and the staff read the flyer to them. The staff offered additional information about the researcher's biography and credibility if the woman asked. Then the woman was given time to consider whether she was interested in participating in the research. After reading the announcement flyers, she was given an opportunity to choose between contacting the researcher herself by phone, or giving verbal permission for the researcher to contact her through their desired contact mode. Out of 26 women approached, all but two women preferred to have the researcher contact them in person while they were at the clinic on that same day they were approached. Only two women gave the staff their phone number for the researcher to contact them later. The initial contact was made to determine the eligibility of the potential participants and, if eligible, to invite them to participate in the study. During the initial contact, all potential participants were given the option to refuse to participate in the study and were assured that their services or benefits would not be adversely affected if they elected to refuse to participate.

Twenty six potential participants were given the announcement flyers. Of those, three were not eligible and were then notified why they were not included in the study. One woman was not the primary caregiver of her husband, another woman was not living with her husband, and the last woman was not caring for her husband at the time of the interview, because he died a month before. Their names as well as the contact information were destroyed once they were excluded from the study. Twenty three eligible women were explained the purpose, procedures, potential risks, and benefits of participating in the study and then were invited to participate. Three women refused to participate because they were not comfortable with the tape-recorded interview format. A total of 20 women were included in the study. All of these women chose to do their interviews at the clinic right after the initial contacts.

Data Collection

Before asking the participant to sign the consent form (see Appendix B), the researcher explained the consent form regarding the nature of study, the potential risks and benefits as well as answer questions the participant had about the study and consent form. Because the researcher was a native to Thailand, she conducted the interviews in the Thai language. To assure confidentiality, most interviews were conducted in a private room at the clinic, moreover, a few interviews were conducted in the empty dining room of the hospital's sports club. Regardless of the location, measures were taken to assure privacy to the best of the researcher's ability.

The researcher informed the participant that she was focused on wives' experiences of caregiving for their husbands living with HIV/AIDS. An open-ended semi-structured interview guide was used initially (see Appendix C). The initial interview was conducted with broad, open-end questions, allowing the participant to articulate thoughts about their experiences from their own perspective. As the data collection proceeded, the interview questions became more focused and directed in response to the conceptual themes that had emerged from the preceding data. As the analysis proceeded, participants were asked new questions in relation to what the analysis showed. In addition, the researcher collected demographic information from participants' self-report through the interview process and completed a demographic form (see Appendix D) at the end of the interview.

All interviews were audiotaped with the participant's permission. The researcher sought to establish rapport by actively reassuring privacy and confidentiality, showing respect and interest in the stories, and being sensitive to personal and emotional issues. Efforts were made to maintain a relaxed atmosphere to decrease participant's anxiety and to encourage the participant to speak openly and easily. The researcher asked open-ended questions in a conversational style to uncover the participants' subjective feelings and details of their experiences of caregiving for their husbands living with HIV/AIDS. During the interview, the researcher carefully listened to the participants with openness, as well as encouraged the participant to tell the stories and articulate the meanings of their experiences in their own terms. The researcher frequently asked for clarification and did not assume that she shared the participants' views or understood the meanings of the participants' words. All information was kept confidential and was not shared with the participants' husband, his health care providers, or others to whom she had not given consent.

At the end of the first interview, the participants who articulated their experience and offered particularly rich data and were willing to participate in a second interview scheduled another interview approximately two to four weeks later. In the follow-up interviews, data analysis of the preceding interviews was verified and confirmed. Although several second interviews were scheduled, fewer second interviews were conducted with the same participants because only five participants showed up for the second interviews. Therefore, the emergent themes and concepts were validated and confirmed through subsequent interviews with subsequent participants. At the end of each interview, each participant was given 800 Baht (US $20) as reimbursement to help offset transportation costs.

Each interviews lasted between 40 to 85 minutes, with an average interview span of 55 minutes. Some interviews were short because they were conducted before the doctor visit, thus the interview was interrupted when the doctor was ready to see the participant's husband. The researcher was the only interviewer in this study. During the interview, the researcher also observed the participant's appearance, reactions, nonverbal behaviors, interactions, situations, events, or issues occurred during the interview as well as the contexts of the interview (i.e. the length of the interview, location, environment, and the nature of the interview). Observational data as well as the researcher's insights or hunches that arouse during the interview were recorded by the researcher in the field notes to facilitate the data analysis and understanding of experience within the participant's contexts.

Data Analysis

According to the grounded theory method, data collection and analysis occur simultaneously and iteratively. Open coding and analytic questions generated from the initial analysis directed the researcher as to what data should be collected, thereby refining questions for subsequent interviews. The purpose of data analysis was to generate conceptual categories, their properties and dimensions from the data, and ultimately generated a grounded theory that explains the phenomena under the study (Strauss & Corbin, 1998). Constant comparative method was used to analyze the data.

The researcher examined the transcribed interviews line-by-line and coded the data, using open-coding techniques. Coding schemes were constantly compared for similarities and differences in terms of their properties and dimensions, and then conceptually grouped into categories. For example, a woman described her exhaustion while she cared for her sick husband. These data were compared and sorted into categories according to their properties and dimensions such as type, degree, frequency, duration, and outcome of the exhaustion, in addition to why and when it occurs. By aligning these properties along various dimensions, specific patterns of exhaustion emerged. In other words, the category of exhaustion varied across the participants along their dimensional ranges.

Once the categories were conceptually grouped in terms of their properties and dimensions, each category was analyzed according to its relationship to other categories. This was accomplished by using axial coding techniques (Strauss & Corbin, 1998). The categories were then related and assigned as conditions, phenomenon, actions/interaction, and consequences to form the conceptual model, called the paradigm model (Strauss & Corbin, 1998). The paradigm model described the women's experience of caring for their husbands living with HIV/AIDS. In the final step of the analysis, the core category of sacrifice was selected. Other categories were organized around this core category to generate an initial grounded theory, using selective coding techniques (Strauss & Corbin, 1998). Data collection continued until the interview data became redundant, and the core category was then fully developed and any gaps in the theory were filled. Theoretical sampling was used to fill in any conceptual gaps.

Theoretical memos were written to facilitate the on-going data analysis in terms of engaging the data, planning of an analytic course, developing of categories and their relationships, and advancing of the researcher's ability to analyze data (Charmaz, 2000). Through out the iterative process of data collection and analysis, the researcher used theoretical memos to document analytical and conceptual ideas as they occurred. These memos contained theoretical ideas, hypotheses, and decisions made about coding, sampling, interview techniques, as well as any changes in theoretical direction and analytic course.

Since the interviews were conducted in Thai language, the audiotaped interviews were transcribed in Thai by the researcher. The researcher did all initial analysis in Thai language under the supervision of two Thai nursing faculty at Mahidol University and the Thai Red Cross College of Nursing, who served as local consultants for the early stage of data collection and analysis. Both consultants earned doctoral degrees from the University of Washington, School of Nursing, and have qualitative research expertise studying Thai women living with HIV/AIDS and family caregiving of PLWAs. During the initial open-coding phase of the analysis, the local consultants reviewed the interview transcripts in Thai, critiqued the interviews, and discussed the open coding with the researcher. During this phase, one interview was selected for translation and back-translation for the dissertation chair to read and confirm the initial analytic processes.

After the initial analysis, and as analytic procedures moved toward axial coding, further analysis was coached by the dissertation chair in the US via e-mails and meetings. In order to facilitate coaching and peer debriefing with English-speaking individuals, two other informative interviews were translated. These two selected interviews, based on the richness and quality of the data they provided, were translated by the researcher into English for the English-speaking dissertation chair to review, verify, and confirm the analysis. To assure validity of translation, one fourth of each translated transcripts was selected and back translated by another Thai doctoral nursing student who had studied in the US for five years. The researcher compared the two Thai versions, and as a result the English version was revised and corrected to assure the accuracy of the translation. This method of analyzing data in Thai and verifying the translation of Thai language in qualitative research has been used previously in other dissertations conducted by Thai students in American Universities (Kespichayawattana, 1999; Phengjard, 2001; Thampanichawat, 1999).

An initial grounded theory was constructed and written in English, as was the report of findings. The English quotations that were presented in the findings were validated by the same Thai doctoral student who does back-translation to confirm the equivalent meanings of the Thai quotations. Word processing software was used in data recording, organizing, and analysis.

Trustworthiness

Traditional validation standards, such as reliability and validity, are not appropriate in grounded theory research due to the nature of naturalistic research and the complexity of social phenomena under study (Strauss & Corbin, 1998). Using the criteria of trustworthiness as identified by Lincoln and Guba (Lincoln & Guba, 1985), the researcher was able to demonstrate credibility, dependability, confirmability, and transferability of research findings. These strategies were employed in this study to established trustworthiness of the research findings.

Prolonged engagement was used to establish the credibility of the findings (Lincoln & Guba, 1985). Trustworthiness was also enhanced by the length the interviews and the researcher's careful approach to establish initial trust and rapport with participants and to generate rich textual data. Second interviews with selected participants were conducted to provide additional depth to capture missing information from prior interviews. The established relationship between the researcher and participant helped the participant express their private thoughts and feelings to enable the participant to share their personal stories rather than public version of the stories (Charmaz, 2000).

Member checking and peer debriefing techniques were employed to increase the credibility of the data (Lincoln & Guba, 1985). During the interviews, the researcher asked the participants to clarify the meaning of their statements when it was unclear. The information provided by the participants was summarized verbally, allowing them to clarify the researcher's views. In addition, the description of tentative findings was shared with the participant in the second interview to confirm or correct the researcher's interpretations of the data. The researcher asked the participants whether they agree or disagree with the researcher's interpretation of their experiences (Charmaz, 2000). In addition to checking the analyzed data with the participants, feedback regarding the data and the analytic process were obtained from the dissertation committee members, and at an advanced qualitative research forum, which consisted of doctoral nursing students and faculty who were engaged in qualitative research. Through this procedure, the researcher's assumptions and interpretations of data were clarified. Feedback from these discussions broadened the researcher's conceptualization of the data, as well as clarified meanings, interpretations, and biases in the analyses.

Both dependability and comfirmability of qualitative research were accomplished through the use of inquiry audit (Lincoln & Guba, 1985). The dissertation chair, and the two Ph.D. Thai nurse researchers, served as the study's auditors. The researcher documented the analytic processes and decisions made at every stage of the research in a journal. The auditors examined the transcribed interviews, the process of data collection, and analysis as being logical, traceable, and acceptable, as well as determined whether the study results were accurately supported by the data. The generated theory could explain what might happen for the population from which it was derived in a particular setting (Strauss & Corbin, 1998). The context of the setting and participants in the research study was provided to the readers as a basis for evaluating the possibility of applying the generated theory back to the population in similar settings.

Credibility of grounded theory was also based on how researcher carries out the research process of generating theory. Strauss and Corbin (1998) offered guidance for evaluating grounded theory research. Their two sets of evaluative criteria involved the adequacy of the research process through which the theory was generated and the empirical grounding of the research findings.

The criteria for making judgment about the rigor and adequacy of the research process were derived from answering the following questions: "(1) how was the original sample selected? on what ground?; (2) what major categories emerged?; (3) what were some of the events, incidents, actions (indicators) that pointed to some of these major categories?; (4) on the basis of what categories did theoretical sampling proceed? how did theoretical formulations guide some of the data collection? how representative of the data did the categories prove to be?; (5) what were some of the hypotheses pertaining to conceptual relations, and on what grounds were they formulated and validated?; (6) were there instances in which hypotheses did not explain what was happening in the data? how were these discrepancies accounted for? were hypothesis modified?; (7) how and why was the core category selected? was this selection sudden or gradual, was it difficult or easy, on what grounds were the final analytic decisions made?" (Strauss & Corbin, 1998, p. 269).

Strauss and Corbin's second set of criteria was related to whether the theoretical findings are grounded in the data. The criteria for making judgments were derived from the answers to these questions: "(1) were concept generated?; (2) were the concepts systematically related?; (3) were there many conceptual linkages and are the categories well developed? did categories have conceptual density?; (4) was variation built into the theory?; (5) were the conditions under which variation can be found built into the study and explained?; (6) had process been taken into account?; and (7) did the theoretical findings seem significant, and to what extent?" (Strauss & Corbin, 1998, pp. 270-272). The proposed study used these criteria to assure the adequacy of the data and ensure that the research process was rigorous.

Human Subject Protection

Confidentiality was the most serious concern when conducting research that involves HIV disease because of the potential harmful social reactions toward the PLWAs and their families if the HIV status was exposed to public. Several strategies were used to ensure the confidentiality of the participants and their families.

For human subject protection, approval was sought from the Institutional Review Board from both Oregon Health & Science University and Mahidol University, where the data were collected. The written permission to collect data from the setting clinic was obtained before data collection began.

Risk and benefits. Each participant was informed of the purpose of the study, potential risk and benefits, their rights as research subjects, and the guarantee of confidentiality. Since the purpose of this study was to describe the experience of women caring for their husbands living with HIV/AIDS, there was no direct benefit. The possible outcome that participants had was being heard and having their experience affirmed. The risk of participating included the potential of participants to feel upset or experience emotional distress during the interviews, as they were reminded of unpleasant experiences. The participants were told up front that they can choose not to respond to specific questions or not to talk about a particular subject as they desired. The researcher was sensitive to the participant's feelings and adjusted or terminated the interview if it became difficult and the participant requested it. Given the vulnerability of the participants and potential concerns about confidentiality of their HIV status, the researcher was sensitive to any signs of discomfort and assured privacy and confidentiality to the best of the researcher's ability. Every participant had the right to discontinue at any time during the interview or to withdraw from the study without any effect on the services or benefits they and their husbands received at the clinic. During the study, if the participants appeared distressed or in need of assistance, the researcher provided referrals to appropriate resources (i.e. counseling service, mental or medical health service, support group).

Confidentiality. The interviews were audiotaped, with the participant's permission, to increase accuracy of transcribed text. To assure the confidentiality, no name was used during taping. Confidentiality was assured through the use of code names and codes. Once the participants had consented, they were given a code name, which did not identify them. Only a participant's code name was recorded in the demographic form and interview transcript. All identifiable information mentioned in the interviews such as the names of persons, institutions, and locations, was removed once the interviews were transcribed, thereby making it impossible to link the data from the interview transcripts and narrative texts in the findings back to particular individuals.

The list of participant's names and code names was made by the researcher to link participants with the data, and was kept in a locked file cabinet separate from the data. This list was destroyed upon the completion of the study. The audiotapes, interview transcripts, demographic forms, field notes, memos, and computer disks containing the data were secured in lock cabinets during the course of study. These data materials will be kept for five years for use in future related research, except the recorded audiotapes were destroyed at the end of the study. The signed consent forms, audiotapes of verbal consent and participant's contact information sheet were stored separately in a locked cabinet. Research consultants, dissertation committee, and a translator were asked to sign a confidentiality agreement form (see Appendix E).

Consent. Signed informed consent was obtained from participants at the initial interview. The researcher read the consent form to two participants who were illiterate. Because of concerns about confidentiality of their HIV status, four participants did not feel comfortable in signing the consent form, and two participants were not be able to sign their names because of illiteracy; informed consent was obtained verbally from the participants and audiotape recorded. Participants received a copy of the signed consent form. Participants who gave verbal consent received a written copy of the consent form also. Considering the potential exposure of the HIV status due to the title of the study shown in the consent form, participants were given a choice to keep a copy of signed consent form or leave it with the researcher.

CHAPTER 4

RESULTS

The purpose of this study was to generate a substantive theory that explained the phenomenon of women caring for their husbands living with HIV/AIDS in Thailand and to identify the process and meanings of HIV/AIDS caregiving, taking into account the social context, cultural beliefs and values of female spouse caregivers. Grounded theory method was used to analyze data.

This chapter presents the findings from interviews with 20 Thai women caring for their husbands living with HIV/AIDS and is organized into three sections. The first section describes characteristics of the sample. The second section is the presentation of the initial grounded theory and the third section is a description of each component identified in the theory.

Characteristics of the Sample

Twenty Thai women, who identified themselves as wives and primary caregivers of husbands living with HIV/AIDS, participated in this study. Their ages ranged from 23 to 50 years old, with a mean age of 34. The majority of women (60%, n=12) in this study were between 26 and 35 years olds and 25% were between 36 and 45 years old. Their education level ranged from primary school to undergraduate college degree, with one woman never having attended school. The majority of women (40%, n=8) had primary education, 30% (n=6) had a secondary educational level, 10% (n=2) had associated degrees, and 15% (n=3) received bachelor degrees. The majority of women (70%, n=14) worked outside the home while 30% (n=6) were housewives. Of those who were working, half worked as employees in the private sector or in government agencies, the others worked as a housekeeper, a temporary worker, a seamstress, a rice farmer, a vendor, and a nurse aid. One housewife reported that she temporarily took over her husband's job while he was sick and could not work. Another housewife was working part-time at home as a seamstress when she had insufficient family income. Of the 14 working women, only seven worked regular hours: two increased their work hours to substitute family loss of income, two quit their jobs to care for their husbands, two were recently unemployed, and one was on sick leave. Participants' family income varied from 6,000 baht per month (about $143 US dollars) to 50,000 baht per month (about $1,190 US dollars) with a mean of 23,215 baht ($553 US dollars) per month. Seven women (35%) reported loss of family monthly income due to either their own HIV illness or their husbands.

Within the sample of 20 women, eleven (55%) women lived with their extended families and nine (45%) lived in their nuclear family. All of the women lived with their husband in the same household. Years being married ranged from two years to 25 years, with a mean of 9.75 years. The majority of the women (60%, n=12) had children, whereas eight women (40%, n=8) had no children. The number of children varied from one child to five children, ranging in age from four month to 18 years, with the mean age being 8.6 years.

Nine women (45%) reported having had an HIV test and that they were HIV positive. Two women (10%) had not yet received an HIV test during the time of data collection and did not know their HIV status. Nine women (45%) reported that they were HIV negative. Demographic characteristics of the participants are summarized in Table 1.

Table 1

Demographic Information of the Participants (N=20)

Demographic Characteristics	Number of Case	Percent
Age		
Less than 25	2	10
26-35	12	60
36-45	5	25
More than 45	1	5
Education level		
None	1	5
Primary	8	40
Secondary	6	30
Associated Degree	2	10
Baccalaureate Degree	3	15
Occupation		
Housewife	6	30
Employee	7	35
Self employed/own business	7	35
Type of family		
Nuclear	9	45
Extended	11	55
Number of children		
Have children	12	60
Have no children	8	40
HIV status		
Positive	9	45
Negative	9	45
Unknown	2	10

By self report, only two out of nine HIV positive women had symptomatic HIV disease. One of them had pulmonary tuberculosis and another had vision loss in one eye from cytomegalovirus retinitis. Women were aware of their HIV status ranging from two months to 10 years, with a mean of 4.5 years. Four women (44.4%) were aware of their HIV positive status between one to five years, three women (33.3%) learned about it more than five years, and two women (22.2%) were aware of it less than one year. All of the women believed that they contracted the virus through sexual contacts with their current husbands. Three women (33.3%) had access to anti-viral medications. Of those, one of them stopped taking the medications because of inability to afford them after the drug trial ended. A summary of HIV infection characteristics is presented in Table 2.

Table 2

HIV Infection Characteristics of the Participants (N=9)

HIV Infection Characteristics	Number of Case	Percent
Time of awareness of HIV status		
Less than 1 year	2	22.2
1-5 year	4	44.5
More than 5 years	3	33.3
Self-reported HIV symptoms		
Asymptomatic	7	77.8
Symptomatic	2	22.2
Anti-viral medications		
Yes	3	33.3
No	6	66.7

The characteristics of the husbands were based on self-report of their wives. Husbands ranged in age from 28 to 45, with a mean of 36.8 years. The majority of husbands (65%) in this study were between 36 and 45 years olds, and 35% were between 26 and 35 years old. Their education level ranged from primary school to undergraduate college degree. The majority of husbands (35%, n=7) had primary education, 25% (n=5) had a secondary educational level, 25% (n=5) had associated degrees, and 15% (n=3) received bachelor degrees. Half of them worked as employees in the private sector or in government agencies, whereas the another half were working in more non-professional jobs, such as mechanic, taxi driver, construction worker, vendor, rice farmer, fish farmer, a launderer/dishwasher, and a business man. Seven husbands (35%) were currently working, twelve husbands (60%) were not working due to HIV illnesses, and one (5%) husband was unemployed.

According to their wives' accounts, two HIV positive husbands were asymptomatic whereas the rest of them had symptomatic HIV disease. Opportunistic infections included: tuberculosis, fungal meningitis, pneumonia, herpes zoster, dementia, retinitis, dermatitis, candidiasis, and lymphoma. The length of time husbands were aware of their HIV status ranged from one month to 10 years, with a mean of 4.2 years. Eight husbands (40%) were aware of their HIV positive status between one to five years, seven husbands (35%) knew about it for more than five years, and five husbands (25%) were aware of it less than one year. The majority of the husbands (60%, n=12) believed that they contracted the virus through heterosexual contacts with prostitutes, mistresses, or ex-girlfriends. Five husbands (25%) did not disclose the source of HIV infection to their wives; two husbands (10%) told their wives that they did not know how they contracted the virus; and one husband (5%) believed that he was infected through an open wound at the barber shop. The majority of husbands (55%, n=11) had been hospitalized at least once, whereas 9 of them (45%) had never been hospitalized. Out of 20 husbands, nine (45%) had access to anti-viral medications. Of those, one of them stopped taking the medications because of severe allergic reactions. Demographic information and HIV characteristics of the participants' husband are presented in Table 3.

Table 3

Demographic Information and HIV Characteristics of the Participants' Husband (N=20)

Demographic Information and HIV Characteristics	Number of Case	Percent
Age		
26-35	7	35
36-45	13	65
Education level		
Grade 1-6	7	35
Grade 7-12	5	25
Associated Degree	5	25
Baccalaureate Degree	3	15
Occupation		
Employee	13	65
Self employed/own business	7	35
Time of awareness of HIV status		
Less than 1 year	5	25
1-5 year	8	40
More than 5 years	7	35
Mode of infection		
Heterosexual contact	12	60
Not disclosed	5	25
Unknown	2	10
Other	1	5
Self-reported HIV symptoms		
Asymptomatic	2	10
Symptomatic	18	90
Number of Hospitalization		
0	9	45
1	6	30
2	3	15
3	1	5
4	1	5
Anti-viral medications		
Yes	9	45
No	11	55

Results of the Study

The generated grounded theory is presented as a conceptual model (Figure 1) depicting the interacting patterns between variables that explain the core process, sacrifice. Using the paradigm model of Strauss & Corbin (1998), categories are linked to the core category, sacrifice, in order to explain the main themes of the theory. Through grounded theory analysis of interview data, six major categories were identified. These categories included: (1) husband's HIV infection and wife becoming a caregiver; (2) Thai culture; (3) sacrifice; (4) sacrificed caregiving; (5) conditions influencing sacrificed caregiving; and (6) outcomes of sacrificing. Each category has many subcategories showing the denseness of grounded theory. A brief synopsis of the theory is described below, followed by more in-depth description of the theoretical concepts and processes.

Synopsis of the Grounded Theory

Husband living with HIV/AIDS was viewed as the antecedent condition, as it sets up the need for caregiving and leads to the central phenomenon of this grounded theory, that being, sacrifice. Women sacrificed their health, their independence and their future by staying with their husbands in order to care for them. For some, this occurred even in the face of seemingly intolerable circumstances. These wives gave up many aspects of their lives and their children lives, and endured many struggles in order to care for their HIV infected husbands. The reasons for staying to care for their husbands ranged from a strict duty to care driven from within Buddhist religious beliefs to a willingness to care driven by love and devotion for their husbands. But whatever the reason, all actively chose to stay, regardless of the sacrifice to themselves or their children. Through this sacrificed care-giving these women learned the skills necessary to care for their sick and dying husbands. They helped their

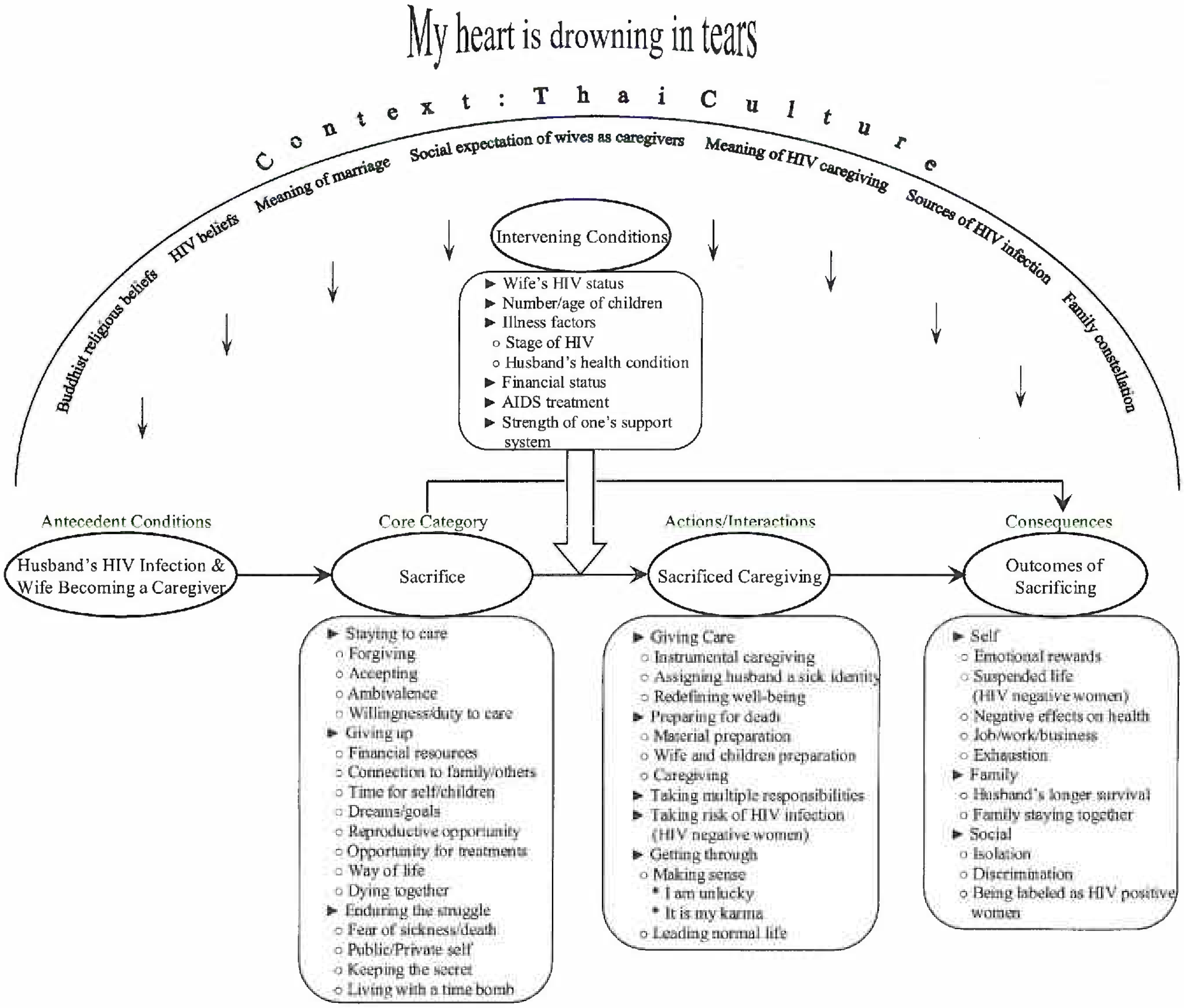

Figure 1. The conceptual model: Experiences of Thai women caring for their husbands living with HIV/AIDS.

husbands and family prepare for death and took on additional, and sometimes overwhelming, responsibilities for the survival of the entire household. They were able to get through it by making sense of their situation within their own beliefs and values and tried to lead as normal a life as possible. How these women actually did the care-giving and the conditions under which this occurred was influenced by a set of intervening factors, such as the stage of HIV illness for both the husband and the wife, number and ages of the children, their financial status, and the strength of their support system. The outcomes of these processes were both positive and negative, involving consequential effects on themselves and their families, and living with the isolation, stigma and discrimination levied on them from the larger society. Enveloped within this entire situation was the huge contextual influence of Thai culture. Underlying and embedded within all the concepts and processes identified in the experience of women caring for their HIV positive husbands in Thailand was the overarching umbrella of Thai cultural beliefs regarding the meaning of marriage and caregiving, the meaning and source of HIV infection, and the role of women in society and as caregivers.

Context: Thai Culture

In grounded theory, context refers to a set of data that explicates the societal meanings and values in which the phenomenon under study is embedded. In this study, the context under which all the other processes and concepts are embedded and hold meaning arose out of Thai culture. Since the meanings of caregiving in this study are so highly contextualized, the data regarding Thai culture is presented first to give the reader an informative base from which to understand the remaining analyses. The major processes of Thai culture important to understanding the meaning of wives caring for their HIV infected husbands are: Buddhist religious beliefs, HIV beliefs, meaning of HIV caregiving, meaning of marriage, social expectations of wives as caregivers, sources of HIV infection, and family constellation.

Buddhist Religious Beliefs

Given that Thailand is a Buddhist country, its beliefs are embedded in the lives of the Thai people, including the participants in this study. Buddhist beliefs about the law of karma provides a template for how women make sense out of their situation. Women perceived that their life was not under their control, but under the law of karma. In this study, karma was the common explanation for any of the suffering, happiness, and or other situations that one could not understand why they occurred, such as caregiving of husbands living with HIV/AIDS and HIV infection. There were two kinds of karma: good karma and bad karma. Karma, as related to AIDS and the situations the women in this study referred to was related to negative things; therefore it meant a bad karma. Bad karma gave negative consequences, such as suffering from caregiving and being infected with HIV.

The following are accounts of how women explained their situation of living with and caring for husbands living with HIV/AIDS, as karma.

HIV negative women accounts included: “It is karma I choose him as a husband.”; “It is our karma that our family has to end like this”; “It is my karma that I can’t leave him, I must pay back for my karma (by caring for him).”; “We had created karma together (in the past life).”; “It is my karma that I have to suffer with him who is unlucky to have HIV.”; and “I think I have karma which I want to pay it all in this life.”

For the women who were HIV positive, some women made sense out of their HIV infection as their karma, while some of them claimed that unluckiness was accountable for their HIV infection. A HIV positive woman explained, “I didn’t do anything, why do I have to bear his karma. I was angry about me bearing his karma". The same woman also said about being a caregiver of her husband, "it must be my karma that this happened to me."

In addition, the concept of merit was also very important. Merit is the Buddhist concept that refers to goodness (Komin, 1998). The concept of merit is closely related to the concept of karma in that making merit is a way to accumulate good karma. One's store of merit is believed to bring a better and happier state of existence in the present and future life (Pohisita, 1998). According to Buddhist teaching, making merit is performed through thought, words or deeds, as well as making oneself of benefit to one's fellow living beings. Taking care of aged parents or a sick family member is considered to be merit making. Some women in this study perceived that they are making merit by caring for their sick husbands. A woman of a husband who is blind because of the HIV-related illness said, "I feel... I do this (caring) for him. I get merit too. Sometimes I thought, I do good thing for someone who can not see, that is a merit."

HIV Beliefs

The category of HIV beliefs consisted of five subcategories: social stigma of HIV, HIV risk perceptions, double sexual standards, misunderstanding about HIV transmission, and meaning of condom.

Social stigma of HIV. Every woman reported her fear of discrimination, that most often took the form of shunning. Women perceived that other people's fear of contracting HIV was the basis for being shunned by them. Even though they did not experience discrimination directly, they protected themselves by not telling others that they had HIV. Only one woman told her mother that she and her husband had HIV. In that case, her mother told others in the village. The villagers expressed their fear of contracting HIV from her.

This participant stated, "Once people saw me, they stepped backward and kept the distance. I'd offer water to them when they visited, but they did not drink it."

Most husbands did not want to go out of the house or go to work if they had AIDS, especially if their appearance had worsened, in order to avoid questions and offensive looks from others. A woman described her experience "I saw how some people looked at us. He was very skinny at that time, but still can walk. We were walking on the street, then people stared at us like….from head to toe, like…turning their head back to keep looking at us. We felt bad that people behaved like this."

Most people in Thailand believe that close contact, such as touching, eating from the same cup, eating together, and living closely with PLWA's can get one infected with HIV. A woman who is a mother of a five year old son said, "My five year old son is very stubborn. I am afraid that he will catch it from me. I don't know what to do; you know… mother and son. Sometimes, he hugged me. I was working and he hugged and kissed my back. I want to push him away, but I pity him. I don't know what to do." Broad-based education about how HIV is transmitted is needed to help people understand how to be safe, while at the same time helping people stay connected to each other.

Thai society holds the view that people who are affected by HIV are bad people. A woman said, "Most people shun us because they think that we have done bad things, so we contracted HIV. So, they shun us." Another woman expressed her fear of being labeled as promiscuous because of Thai beliefs. She said, "Before I am infected, I see others who have AIDS as promiscuous persons. But when I have it myself, I am scared that people will look at me badly. This disease comes from being promiscuous. Others wouldn't know that I have not been promiscuous."

HIV risk perceptions. According to their wives, all the husbands in this study thought that they were not at risk of getting HIV. They had a sense of invincibility in which they thought they could have sexual relationships with mistresses or prostitutes and would be one of the lucky ones who did not get HIV. Women in this study also did not view themselves at risk of HIV. They viewed AIDS as being associated with promiscuous sex with prostitutes rather than anything to do with rightful sex in marriage. Women tended to ignore their husband's before marriage or out-of-marriage sexual experience when it came to HIV risk. It was viewed as none of her business; it is what men do, was beyond her control and was not related to her marriage. Women were more concerned about after marriage behaviors. If their husband did not visit prostitutes, they were safe from AIDS and they were not at risk. If a husband visited a prostitute while married, the wife excused it as just "something men do". One woman, who never thought she would have HIV said, "He doesn't know how he got HIV. But actually, the time he visited prostitutes was the time that he was single. Then he decided to stop and have only one woman. I don't know whether he was promiscuous, but he told me he doesn't want anybody else. He only wanted me. So he stopped everything, drinking, smoking, visiting prostitutes. He turned his life around." This woman regretted that she was not aware of the possibility that he had contracted HIV before he married her, but it never occurred to her at the time. She had believed that she was not at risk. She explained more about HIV. "I am not a bad girl. I live my life normally, like my friends and everybody else. I am not a girl who smokes and goes out to the night clubs. I am not like that. I don't like it. When I see those women I thought that they are kind of not afraid of anything, how they speak and express themselves. Then, a woman like me to have HIV! Those women should be the ones who have HIV, not me."

Double sexual standard. The data about how Thai men contract HIV reflect a double sexual standard that is common in Thai culture. Although having affairs is not socially acceptable, it is common in Thailand. Three women in this study had husbands who contracted HIV from their mistresses. One husband kept having affairs with more than 30 women in the past 23 years because he perceived that it is acceptable and having sexual relationships with many women was his personal pleasure and there was nothing wrong with it as long as he continued to support his wife and family. Another husband continued his affairs even after he was HIV positive. His wife explained, "He may have a wrong idea. For example, he loves to watch soap opera shows on TV where the male leader has several women. He is a very smart man; he manages the girls not to know about or see each other. He mimics the soap opera shows. I notice that he feels that he is smart and good at it". All wives were hurt emotionally but they did not seek divorce because of these affairs. They accepted him back, despite these affairs or visits to prostitutes, even when he had HIV because of it. Patronizing prostitutes and having multiple sex partners are a part of Thai male society.

Misunderstanding about HIV transmission. Before getting their HIV tests, all of the participants had assumed that they must be infected by HIV. Out of twenty participants, eighteen decided to get an HIV test, two refused to be tested but assumed that they were HIV infected. For those who had an HIV test, nine of them were HIV positive, and nine of them were HIV negative. Of those nine HIV negative women, six stated that they were happy that they did not contract HIV from their husbands; three of them were ambivalence about their HIV status and felt that they should not let their husbands die alone. This issue is discussed in more details under the category of "dying together".

The nine HIV negative women were in disbelief that they did not contract HIV from their husband. They do not understand why they were not infected even though they had been exposed to HIV before their husbands were diagnosed. They believed that anyone who had even one sexual contact with a PLWA would certainly get HIV. Since they had sexual relations with their HIV infected husband without using condoms for a period of time, they assumed they must be infected.

Another misunderstanding was that any wife of HIV infected husband would get HIV eventually whether she took precaution or not. One HIV negative woman believed that she will certainly be infected no matter what she does from this point out because she was the wife of husband living with HIV. Therefore, she did not take full precautions while caring for her husband. She said “No matter what, I will get infected anyway. Every case in my village, they all are infected. Not a single one escapes it. Now I know that I am not infected, but one day I must be.” What she is implying is that it is useless to seek protection at this point because it is just a matter of time before she too becomes infected, regardless of anything she could do. This belief has staggering implications for social policy.

Another HIV negative woman who worked in the health care field still did not understand why she was not infected after years of living with her HIV infected husband. “I am never confident that I am not infected. Every time someone asks me, I feel unconfident to say that I am not infected. My feeling is that I should be infected 100% because I did not protect myself at all. I still wonder why?”

In addition, husbands in this study have a belief that if they ejaculate outside the female body, she will not contract HIV. Another misunderstanding was that women will develop HIV symptoms later than men because they have a period to release the virus out of the body.

Meaning of condoms. A condom is a symbol of disgust or shunning. Some women and their husbands perceived wearing a condom as an act of alienation, which then leads to feelings of rejection and isolation. It is related to similar meaning associated with wearing gloves when providing caregiving for their HIV infected husbands; that their wives are ashamed and disgusted by them. Again, this has multiple social policy and patient education implications.

Meaning of Marriage

How women defined marriage strongly influenced the decision to stay with and care for their husbands. The meaning participants' ascribed to marriage was also influenced by Thai social values. According to the participants' views, marriage was perceived as a long-term commitment in which persons are committed for their entire life. Perceptions of marriage were reflected in the women's accounts: "I did not leave him because, no matter what, we've already spent our lives together. We will stay to take care of each other until we die.", and "we already are a husband and wife. I can't leave him."

In addition, marriage means "joining lives as one" and the "sharing of both suffering and happiness". A woman noted, "People…when they are married, they are like one person. They have to share both suffering and happiness…must share everything…able to talk, laugh, and cry together. Whatever they go through, they must stand by each other side."

Women perceived that it was morally wrong to leave when their husbands were in despair, such as sickness, and in need for help. A woman talked about her husband, "because he is sick, I am not cruel enough to leave him. When he is well, I often say you should go away, but every time he is sick, I don't dare to say that."

Many women thought about marriage in terms of a tie that creates the family structure for children. A woman does not leave her husband because, "At least I make my child a warm and completed family. Not like…father goes this way, mother goes that way. My child has both father and mother."

Gratitude is another strong social value in Thailand. When a person has done something for someone, he/she owes gratitude to that person. Some women applied this value to their marital relationship. Because their husbands have been good to them in the past, for example, being a family man, or a good provider, women felt grateful to him and provided care in gratitude for his merit. A woman said "…if it wasn't for him, I wouldn't have today. I think like that. I think I care for him in gratitude for the good things he has done for me. If I didn't have him, I don't know what I would be today."

Social Expectation of Wives as Caregivers

In Thailand, it is a social expectation for women to take care of their family members. This social expectation influenced the participants' decision-making process regarding whether or not to stay with their husband once it was discovered that he had HIV.

All of the women in this study assumed the role of caregiver when their husbands were sick. Most women perceived that they had a duty to care for them when they were ill and that they must take on this responsibility in order to be "good" wives. The participants often described their feelings about caregiving for their husbands as performing a duty.

Growing up in a family with traditional values, a woman was raised as a "giver" to her family. She said, "….it (caregiving) is definitely my duty and if you ask about my willingness, it is also willingness in a way that it is my duty. My family raised children to be responsible to their duty. When I was with my parents, when my father sat at the table, the food must be ready. When we finished our meal, the daughter cleared the table. Sons never did that, it is daughters who did. We were raised to help out with chores from morning to dark, cooking, mopping. If we didn't do the dishes, we were beaten when we got back. So, it was built into our habit that this is our duty. We do it as it is a normal thing to do without feeling anything. It becomes a normal way of life."

As for HIV/AIDS caregiving, women perceived themselves as being in the best position to take on the caregiver role, because they were wives. All women in this study felt that they were obligated to care for their sick and dying husbands, because it was their duty and that was what good wives should do. Most women in this study felt that they were in the unavoidable or nonnegotiable position to provide care when their husbands were sick. It is not culturally appropriate if wives passed on that responsibility to other family members. Some women in this study expressed their disapproval toward some wives they saw leaving the responsibility of caring for their HIV infected husband to others. They viewed women who did such a thing as bad wives.

In addition, some women expressed their concern of being condemned by their husband's family, neighbors, or community if they did not provide good care to their sick husbands. "…It is the duty. If I think that he is out of my sight, then that is it. But here he is--right there in front of my face. How the outsiders will look at me. Supposed I leave him, I don't give care to him. My husband is sick, but I wake up in the morning and go out to socialize at somebody's house. They are outsiders, they don't know what it is like inside the house, but in their view, I will certainly look bad. Because I am here in this situation, it is like my responsibility, my duty. I must perform my duty the best I can, so when I go out, people can't blame me or gossip about me. Actually, my husband wouldn't say bad things about me, but his family may, spread the words from one person to another. Good things I have done for a long time would be forgotten because of bad actions I did in just a few days of non-caregiving."

Some women perceived themselves as a care provider because females are born with the ability to care. These women perceived that caregiving was a woman's job and that they could do it better than a man. Therefore, they should be responsible for the caregiving of family members. Their husbands' family also expected their sons' wives to be the first persons to take on the caregiving responsibilities if their husbands were sick. A woman noted, "His sister keeps telling me that I have to take care of her brother. I must encourage him and care for him." Another woman shared her experience that her mother-in-law expected her to be the primary caregiver of her husband at the hospital even though she was very tired and did not get enough rest. The mother-in-law was upset when her husband asked other family members to help caring for himself instead of his wife.

Meaning of HIV Caregiving

The accounts of the participants in this study provided insight into the meaning of HIV caregiving, as perceived by Thai women caring for their husbands living with HIV/AIDS. HIV caregiving was a representation of a woman's sense of love, warmth, care, sympathy, attachment, companionship, duty and obligation for their husbands. Caregiving was a purposeful action to save and extended their husband's lives. The care performed was aimed at maintaining and restoring husbands' well-being and eliminating physical and emotional suffering. Caregiving consisted of physical and psychological care. Emotional care was perceived as staying in the marriage, not shunning one's husband, and taking the risk of becoming infected HIV infection. In addition, the meaning of HIV caregiving was associated with the Buddhist belief of merit, in that giving care was merit making. On the negative side, caregiving was perceived as the fruit of wives' karma, as well as husband's karma, which their wives bear the brunt of.

Sources of HIV infection

Most of the husbands in this study contracted HIV from heterosexual contact and all HIV positive wives contracted HIV from their husbands. Several husbands in this study contracted HIV from prostitutes either before or after marriage. Some were infected from their mistresses. How husbands contracted HIV resulted in different emotional responses from their wives. Source of infection determined whether husbands should be blamed, for which wives should be angry, and how difficult it was for women to come to terms with their husband's infection.

One husband claimed that he contracted HIV from a haircut; another claimed it was from an ex-girlfriend. These were acceptable sources of infection, therefore, their wives were not angry at them because they felt that it was not their fault, and therefore, they should not be blamed for their HIV infection. On the other hand, unacceptable sources of infection such as visiting prostitutes, or mistresses, caused women a great deal of anger, because their HIV infection was considered a result of their bad actions and that the husbands brought HIV onto themselves. However, the time husbands contracted HIV was another factor in judging them. Although the husbands got infected from visiting prostitutes, if it happened before they were married, they did not deserved to be blamed for anything other than their ignorance to protect themselves. Women were not angry at these husbands because they did not cheat on them. Besides, there was nothing culturally wrong about a single man patronizing prostitutes. On the other hand, post-marital HIV infection created a great deal of anger in most women. All of the husbands who visited prostitutes after marriage concealed their behaviors from their wives. Then, HIV diagnosis came with the revelation of the husband's unfaithfulness. Although women perceived that what their husbands did was wrong and they were angry at them, initially, ultimately, they were able to come to terms with their wrong doing.

Some husbands refused to tell their wives how they got HIV or kept silent about the source of their infection for a long period of time. In these cases, women were caught in the turmoil and could not come to terms with the HIV infection. However, women finally gave up their quest and accepted it. One woman explained her husband's response to her request about the source of HIV infection. "I asked him, but he never told me. I told him I wanted to know. He was just silent. After I learned about his infection, I was angry. Every time I thought about it, I wondered how he got it. But now, I don't care anymore. I gave up asking him."

Women who contracted HIV from their husbands were angrier than those who were HIV negative. HIV negative women perceived that how the husbands got HIV was their business and since the HIV infection did not directly affect their lives, besides the fact that she had to care for them, they were more able to accept it. It was harder for HIV positive women to come to terms with their own infection because it was the result of their husband's unfaithful actions and they had to bear the deadly consequence of their poor choices.

One woman did not perceive her husband affair as unbearable. However, she was angry at him for not protecting himself from HIV while doing that. She noted, "I am only sad, but never blame him, never scour him, never condemn him. But I resent that I warned him, but he never listened to me. Once it happens, it is hard to resolve. Only if he protects himself, if he is promiscuous, but protects himself, it is okay. But ,he did not protect himself at all."

Family Constellation

Several women in this study lived with their extended family, either their own or their husband's family. It was the family's expectation that wives should be responsible for the care of their husbands when they were sick, not anybody else in the family, even if they were able to do so. If women received help from their extended family, it was only in the form of assistance to relieve their caregiving burden occasionally, rather than taking over the caregiving responsibility totally.

A woman whose husband was hospitalized for a month said, "I had to come visit him and care for him in the hospital everyday, otherwise his family would blame me." Even though her husband had his mother or sister there with him everyday, the family felt that she should be there also, because it was her duty to care for him.

Living with her husband's extended family created stress for some women. The first reason was that they did not have full authority to make decisions in caregiving of their husbands. Secondly, women perceived that they were not welcome to stay with the family after their husband's death, since their husbands' family would not need them there after they had done their role of provide the caregiving. Women expressed their thoughts about moving back to live with their own family but were concerned about burdening them with their sickness in the future. A woman noted, “I will move back to my parents’ house. I can’t stay at his house, because nobody understands me. His sister has been good to me, but it is impossible that she will care for me when I am sick. She has to work. Taking care of me is impossible.”

Antecedent Conditions: Husband’s HIV Infection and Wife Becoming a Caregiver

The antecedent (or causal) condition is that set of events that influences the central phenomenon and creates the need for the core social process to occur (Strauss & Corbin, 1998). In other words, if not for the antecedent factors, the central phenomena related to the core category of the grounded theory would not have to be set in motion. In this study, these two conditions, the husband’s HIV infection and his wife becoming his caregiver, required the need for the central phenomenon of sacrifice and sacrifice caregiving to take place. These two conditions will be described briefly.

Husband’s HIV Infection

Heterosexual contact, either before or after marriage, was the major source of the husbands’ HIV infections. Most of the husbands discovered they were HIV positive after marriage. One participant’s husband suspected that he had HIV, but did not get tested before marrying his wife. Two men were diagnosed with HIV after they had sexual relations with the participant, but before getting married to them.

Most of husbands were diagnosed with HIV/AIDS when they were sick and received treatment for HIV/AIDS related illnesses. A few of the men were healthy but got tested for HIV anyway because of the need for screening related to pre-pregnancy planning, life insurance or job applications, or because they believed that he may affected by HIV because of a sexual partner dying of AIDS, or when his wife tested HIV positive during prenatal care.

Wife Becoming a Caregiver

Although many Thai women leave their husband once they are diagnosed with HIV/AIDS, the women in this study were the ones who decided to stay with their husbands and provide care for them. Because they were married to an HIV infected husband, and they had decided to stay in the marriage, it was left to them to provide the care they needed. Once the couple learned about the HIV infection, the wife knew that her husband had a deadly disease and would need someone to care for him when he was ill, until he died. Thus, she realized that he needed her to care for him. Some women began her care-giving as soon as she learned about his diagnosis, in a form of emotional care. Some women, though, assumed the caregiver role long before the diagnosis was made since their husbands had been ill for a period of time. In this study, most of husbands were sicker than their wives, thus the wives were responsible for their care. There were two women who were also sick while caring for their sick husbands. These couples were caring for each other when the other partner was sick.

Because of the effort to conceal the diagnosis, several women in this study were the sole caregiver of their husbands. A woman described how she became a caregiver, "he doesn't tell anyone but me that he has HIV. There are only two of us who know. So, when he is sick, I am the only one who cares for him." To avoid discrimination and rejection, most women did not present themselves to others as the HIV/AIDS caregiver of their husbands living with HIV/AIDS, but rather as a caregiver of a husband afflicted by other diseases, such as cancer, leukemia, pneumonia, TB, etc. In many occasions, the caregiving activities women performed were hidden, as may have created suspicion from others. Wives' caregiving occurred both at home and at the hospital when husbands were hospitalized.

The Core Category: Sacrifice

The core category in a grounded theory is the most pervasive and central explanatory concept pertaining to the phenomena under study. The core category is the "heart" of the theory and explains that set of data that was the most meaningful in explaining the phenomena. In this study, the core category was sacrifice and how sacrifice was manifested when living with a sick and dying husband. The process of sacrifice depicts a social process of Thai women engaged in when caring for their husbands living with HIV/AIDS.

The core category consists of three sub-categories: staying to care, giving up, and enduring the struggle. The experience of Thai women caring for their husbands living with HIV/AIDS was viewed as a process of living with a sick and dying husband in which wives made a series of sacrifices in choosing to stay to care for their husbands, giving up what they had or should have had if it were not for their husband's illness and learning to endure the every day demands and struggles associated with providing care.

Although wives caring for husbands dying from other terminal diseases have many of the same difficulties as the women in this study, wives of men with AIDS had additional struggles and sacrifices other wives do not have to make. The source of the men's HIV infection and its transmission was integral to the women's experience with the caregiving they performed and the sacrifices they made. Because their husbands made choices to seek sexual gratification outside of marriage, were unfaithful and/or engaged in behavior that was viewed as socially unacceptable, and because it appeared to others that he just "did it to himself', the social stigmatization against PLWA's and their families was extremely high. Although many women in Thai society were unable to forgive their husbands and did not want confront the fear of also being infected with HIV, the women in this study all chose to stay in the marriage and care for their husbands, even though it caused them emotional pain and, for some, even transmitted the HIV to them. By doing so, they made the sacrifices required of them and learned to overcome their anger, to give forgiveness, to accept the consequences of their husband's actions and to endure the emotional struggle that the care-giving mandated. The women in this study who chose to stay with their HIV infected husbands sacrificed their well-being, and in some cases contracted HIV themselves, for their husband's benefit.

Staying to Care

Staying to care referred to the process woman experienced when their husbands were diagnosed with HIV and consisted of four internal processes: forgiving, accepting, ambivalence, and willingness/duty to care.

When HIV entered their lives, it changed their lives dramatically. After leaning that their husband had HIV, women knew in their mind that their husbands were terminal and were going to die because of AIDS. These wives were terrified of their future because of the nature of HIV disease being deadly, contagious, and highly stigmatized. Women acknowledged that their husbands needed someone to support and care for them when they became sick or suffered from the more severe HIV symptoms at the end of life. Some of them were terrified when they leaned that their husbands passed the deadly virus to them. For those who were "lucky" and not yet infected by HIV, there was fear of future transmission. For some women, the diagnosis of HIV led to the disclosure of the husband's unfaithful acts, which resulted in contracting HIV.

All of the women in this study had a choice to leave their husband and most of them thought about it at some point. After thinking through and internally debating between staying and leaving, they decided not to leave. Women described different reasons to stay and care for their husband. Usually, there were multiple reasons in a woman's decision.

Many women were loyal to their husbands, especially when they were sick and felt they could not leave their husbands. One HIV positive women said, "Before he was infected, I could divorce him. But after he was infected, I don't want to….well, I know that he has this disease. I don't want him to think…like…when I have AIDS, you leave me. Even if I am not infected, I won't leave him. What ever happens, I will care for him, but I am also infected. I am afraid that he will feel bad…"

Some women described their reason to stay because "he is my family", "he is a father of my children" or "we have children together". A women explained, "(he is) my family, there is a tie between us because no matter what, he is my husband. Whatever he is, we already join our life together...in other words, we attach to each other. We have lived together…"

"He already made a mistake, what can we do" or "already infected, can't do anything about it" or "it already happened, take it as it is" were frequently mentioned by women.

Several women noted that their husband's good behaviors in the past was a major reason for staying. A woman whose husband was a good family provider and had been a good partner to her was reason enough for her to stay. "Before he is very good person… have been very good. So I think about his goodness. So when he gets sick like this, I can't cut him out of my life. I still think about his goodness."

Some women stay with their husband because of their moral values. They cannot leave a sick and dying person to die alone. A woman decided to stay because "I can't leave a despaired husband who is sick and dying, if he is healthy I can leave him." With the moral value she held, a woman decided to stay with her husband. She noted, "if he doesn't have me, he won't survive. He may not die of the disease, but he will commit suicide. If that really happens I can't live with it. I may not be able to live with it if I leave him. So I give in. I rather stay with him." Some women care for their husband because they think they are doing a good deed, making merit or good karma, or paying back for past karma in this life to be free in the next life.

Many women described the feelings of attachment, love, sympathy, and loyalty as the reasons to stay and care for their husband. A woman said, "It's the attachment, love. And we have been together with out any problem. I care about him. I love him, I look after him. I think he is the father of my children. I love him, worry about him." Another woman had a strong bond with her husband, "It is the connection that we had. We went through trouble, and we were still together. Having AIDS is less trouble. Why we can't stay together." Another woman expressed her loyalty to her husband, "I will never leave him. After all, we had already spent our lives together. I will stay by his side until death do us part." Some women stay for the sake of their children. She did not want their family to break; she wanted her children to have both parents.

The women in this study had a variety of emotional responses to these situations. Given the above circumstances, women internalized these feelings and figured out a way where they could stay in the marriage. These cognitive processes were: forgiving, accepting, ambivalence, and willingness/duty to care.

Forgiving. Initially, all nine of the HIV positive women in this study were angry that their husbands contracted HIV and passed it on to them. Some critically condemned their husbands of killing them, "It is like he kills me"; "He is cruel, he took me (to die) with him. He doesn't die alone." However, most HIV positive women came to believe that their husband's did not give them HIV as an act of killing. They never used the word "kill" but "he passed HIV to me". They made the distinction of intent; their husbands did not intend to kill them by becoming infected with HIV and passing it to them through sexual transmission. Rather, the result was that they were going to die because of their husband's actions, but not because their husbands wanted that to happen. He just "passed HIV to me" and my death is a possible result.

It was easier to forgive if the husband contracted HIV before marriage, since that was not viewed as being unfaithful. Rather, the wives viewed it that he contracted HIV because he was young and naïve and that was what young single men do; they visit prostitutes. This social belief, that it is acceptable to visit prostitutes, is prominent in Thai culture. They believed that their husband's did not know they had HIV when they got married because "nobody wants to have HIV and pass it to his wife". Although angry at his careless act, women think their husbands deserved forgiveness in these situations. Additionally, if the husband admits his wrong doing, and says that he is sorry and that he is willing to turn life around to please her, women were more able to forgive him. In the cases where husbands never told their wives how they got HIV, these women were not able to totally forgive their husbands, but came to terms with it in their own way and gave up their desire to know how it happened.

For the three women whose husbands had affairs or had mistresses, they also were able to forgive their husbands. Of these, two women were not infected and one was. Although the one wife infected with HIV from her husband was angry that he had transmitted HIV to her after contracting it from his mistress, she was able to accept it and chose to stay with her husband and care for him. This HIV positive wife had been dealing with husband's off and on affairs with more than 30 women in their 23 years of marriage. One of her husband's mistresses died of AIDS, so she decided to get HIV tested after her neighbor warned her that her husband might contract HIV from this mistress. She was HIV positive and so was her husband. She was very angry, sad and terrified, but her husband regretted his actions, turned his life around, ended his affairs, and began to take care of his family. His wife sympathized with him and forgave him. "I know that we got infected, that was already passed. I didn't blame him. Never. I only said to him…see…because you are infected, we have to suffer like this. He said he feels very sorry for me, but he doesn't know what to do. He said, he made a mistake, he can't fix it….I forgive him. Never scorn him. Now I am not mad at him." Since the diagnosis, her husband has spent more time with her and pleases her more than he did in the past. "I sympathize with him because he was lost for a while…no, not a while, it was 23 years he is like this (having sexual relationships with other women)". So, although these women felt angry, terrified and betrayed, they forgave their husbands and chose to stay and care for them. Although most women in the study were angry, they also felt sorry for their husbands since they were sick and living with illness and shame of their actions. Because of that, the women in this study believed they deserved forgiveness.

Most of the women did not offer forgiveness in words, but did so in actions. Forgiveness was presented in the forms of being by his side, giving emotional support, and caregiving. Some women implicitly forgave their husbands simply by accepting the situation and no longer talked about what he had done to her. One woman, an HIV negative woman was told by the doctor that her husband had HIV when he was very sick and unconscious in the hospital. They never talked about his infection after he recovered from his illness. "I was very mad at him, but I didn't say a word to him. I was silent and only think to my self. I was angry but never tell him about my anger because he is sick. I don't want him to die quick."

For women who were able to forgive, there were many reasons of their forgiveness, including: they believed it was an unintentional act of getting HIV and passing HIV to her; it was his only mistake; if one condemns, blames or fights that will only make the situation and his health worse; his past goodness overcame his mistake; and they are not able to change what already happened, so one needs to forgive. One participant said, "It is already happened, can't correct it. If I angry at or hate him, he will die sooner."

Not all women were able to completely forgive their husbands. For some women they were only able to accept the situation. "I was angry. I was hurt. When he was with me, why he had it (sex) only once in a while, but before he had me, why he has to visit prostitutes. I said to him. Sometimes, I was furious and want to run away or take my own life, but I thought about my son. I worry about him that he will have a problem if I leave." So, she learned to accept that this is how it is.

Accepting. Another aspect of staying was the process of accepting the situation and choosing to live with and care for their husbands. After many of the women learned to forgive their husbands and resolved their anger, women accepted what life brought them. In this process, women began to internally accept caregiving responsibilities and hardships such as social discrimination and financial burden, which accompanied the decision to stay. Women realized that staying and caregiving went hand in hand; if she decided to stay, she had to provide care to her husband sooner or later. Therefore, in the women's mind, the reasons to stay were the same as the reasons to care.

Influenced by Thai social expectation of women to play the role of caregiver, most women felt it was a wife's duty and obligation to care for her husband, and accepted this as normal. "It is normal that wife has to take care of husband, like siblings take care of each other." Women's sense of duty and obligation were influenced by Thai cultural value that families take care of their sick family member, as well as the social expectation about wife as a caregiver for their husband. A woman said, "…the reason I do things for him is that it is my duty that I must do. If I don't do it, who will do it for him? If I leave him, he will live alone." Another woman described, "Sometimes, I told him I won't even look at him when he is sick, but when he is sick, I have to take care of him. It is the duty…after all, I am his wife, and I must do it."

Some women accepted the role of caregiver as her duty as a wife. Therefore, they simply accepted the caregiving responsibility with out any objection. A woman said "Here I am, in this position (wife). It is like my obligation, my duty. I have to perform my duty the best I can"; "I guess I do it because it is the duty. If I leave him, he has no one else. He doesn't tell his relatives". Other women viewed that their marriage had tied them together and that made them feel responsible to stay together. Another woman noted "We have already lived together as husband and wife, so we keep on living together and take care of each other"

Other women stayed with their husband because of their moral values and accepted this as part of who they were. One woman was afraid of feeling guilty if she left her husband and he committed suicide. She said, "I am afraid that I will be the cause of his death. He said that if he doesn't have me, he won't live. That made me think. If he dies, it means that I kill him and I will feel guilty for the rest of my life" Other reasons include the husband's benefit such as helping husband to live longer and not making him feel abandoned or shunned.

It is important to note that every woman had multiple reasons to stay and care for their husband. For example, a wife felt sympathy and saw his past goodness as the reasons she decide to stay, but also perceived that it was her duty to care for her husband.

A women whose husband contracted HIV from his mistress, described multiple reasons of not leaving her husband. "I can't leave him. Well, it is many reasons combined, the love, the connection. Besides, it was already happened, and we don't know how long we live, and we will have children together. My child cried when I told him we are going to separate. He can't pick whom he will live with." In all, these reasons to stay stem from the belief that it is important to accept one's situation as it is, especially if its already happened and there is nothing that can be done to change it.

Ambivalence. Whereas women made a choice to stay with their husbands and care for them, over time some women began to question their decision. Some women felt a great deal of ambivalence about whether to stay or leave the relationship in the midst of their care-giving struggles. Although they did not leave their husbands, they often experienced ambivalence as to whether or not they made the right decision as they endured the everyday reality of their emotional struggle of giving care.

An example of this was with one HIV negative woman who stated she started out with a strong feeling that she would stand beside her husband and support him, but after facing many difficulties in caregiving, she became more and more ambivalent when she did not receive the appreciation and assistance from her husband and family that she thought she deserved. She described her ambivalence as "It is always like….do I back up or step forward." She explained, "I don't know why I keep him. I don't understand myself. He doesn't help me with anything. May be, I still have karma. But…I want him to stay with me a long time…I don't know…it is like my mind is fighting with each other. He is alive, so he is a burden. But if he is gone, so I am alone…feeling lonely… (Chuckling). I don't know what I want." This woman experienced more doubt when her husband was very sick or when she felt exhausted or emotionally upset.

Another HIV negative woman, who had lived with her HIV infected husband for 8 years, stated that she devoted herself to care for him because of love and hoped that her staying and caregiving would make him behave better and end his extra marital activities. She noted, "I want to care for the person I love as doing good deed for him. He is not a good man, but I thought my goodness will change him. I have been good to him, but I get bad things in return. I did my best. Anything I could I did for him. In the past, I stay with him because I fond of him, but now, I am not sure. My feelings changed after having lots of problems." Despite her ambivalence, she remained with him because she felt she could not do anything else at that point and did not want to feel guilty in the future about leaving him to die alone.

Willingness and duty to care. The process of staying to care can also be explained as a dimension or continuum, with willingness to care on one end and duty to care on the other. What made women stay and perform care activities ranged from those being willing to perform care to those feeling it was their duty to perform care. There were women participants in the study who ranged from one end of the continuum and were willing to give care because of love and because they felt good about it and women who gave care mainly because it was their duty, and then there were women along the continuum who had mixed reasons to care. The degree of each reason determined how women feel about their caregiving experience.

Women who provided care with a sense of love, attachment, loyalty, sympathy, or companionship were more willing to care and had less struggles with their caregiving tasks than those who provided care because of duty or obligation. These women were willing to provide care with their heart filled with love, attachment, loyalty, sympathy, or companionship and they were totally devoted to care for their husbands and were able to endure the difficulties without feeling ambivalent about their decision. They were able to keep positive attitudes toward caregiving. The following is a HIV negative woman's response to the question about how she felt about giving total care to her husband. "I don't know. I don't want him to get tired and I don't want him to get too sick. I sympathize with him. I thought I am healthy. I get tired then I get better and it will be gone. I can eat anything I want, but he can't. I can do anything I want. I am exhausted, I get some rest, and then I am fine."

Women who were willing to care did not resent their husbands or their caregiving work no matter what he did. They were willing to sacrifice their well-being for their husband's benefit and not expect anything for themselves or for their own benefit. They were satisfied with their caregiving and thought that if they did good things they would not have to look back with regret. As one HIV negative woman said, "I never complain, not even once that I am tired. I never tell him that today I am exhausted. I feel that I do for him because I am willing to do….if I love that person, I don't feel bored or tired…it is…like I feel I am willing to do. After he dies, I won't feel sorry for the past, because I do every thing to the best of my ability. I won't regret that I should speak to him better than I did. I will always treat him nicely. I will devote to him as much as I can." Women who performed caregiving willingly stated that they did not mind the hardships and that they did not perceive their caregiving as burdensome to them. A woman said "Last night, I wasn't feeling well after I got back from work. I checked on him, then I took a nap. I woke up and warmed him a glass of milk. I don't know, I feel like even if I am sick I have to take care of him. It is like…I want to care for him."

Another woman who provided care for her husband with deep love and strong attachment said "My husband said that he troubles me. I said no, not at all. He never caused me any trouble. Don't even say this word. He never does (trouble her). I do… do… do… everything nowadays only because I want him to get better… I never get tired. I never feel that he is my burden….I can take care of him and never feel tired."

Women who stayed to care for their husband because they felt it was their duty or obligation, had a harder time. They had more difficulties getting through the day-to-day hardships that come with the daily demands or caregiving. Sometimes, they resented their husbands and questioned their decision to stay with and care for them. They felt that they sacrificed enough and should not be expected to do more. Sometimes these women resented their decision to care because they did not get what they hoped for in return, such as a supportive companion or a husband who could work to support his family again.

One woman who cared for her husband because it was her wifely duty, stated that she felt obligated to do so because he had helped her family in the past. She was physically and emotionally exhausted from unrelenting caregiving, and she did not receive any support and encouragement from her family in return. She struggled to keep on doing what she was doing, but felt that she had to do it. It was hard for her to endure the hardships. "When I do things for him, I just do them and don't think much, but don't say thing that hurts me emotionally, I resent it. My heart is like a glass. Look at it from outside, it looks okay. But inside, it is ready to break at any time. Keep performing my duty like this, I can do, but don't hurt my feeling…When he does something that hurt my feeling, I thought I care for him for what. Why do I stay? I have to deal with his bad moods, but everyone gave me nothing even my daughter. It is like what I do nowadays, I don't get anything. Even I want something for myself, I don't dare to buy it. I thought we won't have enough money for his future care"

Another women described performing her duty to stay with her husband and care for him, "no matter what, he is not out of my hands; I can't shove my responsibility to others." Her husband's relatives were helping her care for him prior to his HIV diagnosis. Once they learned that he had HIV, they shunned and abandoned him and left her to care for him alone. She did not want to care for him but felt she had to because it was her duty and she was obligated to him since he provided for her parents in the past. Not only did she not receive help from his relatives, she was openly criticized by them about how she performed the care.

She said, "I am fed up with my husband. I am tired. He is a stupid patient. He doesn't take his medicine. I am very busy, but he always needs me to remind him to take medication.... I am very discouraged. His relatives condemned me that I didn't mean to save him and find him good treatments. Actually, I did. I have spent 200,000 Baht for his treatments. I can endure hard work, but don't anyone blame me, I don't like it".

Giving Up

Another category of sacrifice was giving up. Because women lived with and cared for their husbands, they were forced to give up, or lose, many important aspects of their lives. Women lost much of their financial resources, their connections to extended family, time for themselves and their children, opportunities for their own medical treatments for HIV, reproductive opportunities, dreams/goals, their previous pleasant way of life, and opportunity to live, not die, with their husband.

Financial resources. HIV medical treatments and care were very expensive. Being rich or poor was not a factor for these women. All of them sacrificed their family's financial future in order to get the treatments needed to save the husband's life, which would allow him to live longer. Money was spent primarily for his medicines, alternative treatments, and special foods and supplemental diet items.

One woman said, "My salary, I spent them all on vitamins and dietary supplements. Every brand I bought for him about 30,000 Bath a month. My husband said that I throw my money away for him. I said it is okay."

Another woman took her husband to several places for medication that people told her would cure AIDS and wasted a lot of money on scams. She said to the doctor at the hospital, "I am willing to pay. I am not a rich person, I don't have much money, but I can find money to help my husband, to give him the best treatment" She lost her saving but still had her income, "I never complain about anything. No matter how expensive it is, I will pay. On his first visit, I brought 30,000 Bath, the doctor said it won't cost that much. So, I paid around 10,000 Baht on that visit to get him full exams. The doctor teased me that he rips me off. I told his doctor it is totally okay."

Women who could not afford to pay for treatments from their work salaries or from savings, sought other ways to find financial resources to care for their husbands. Some women sold their cars and land, worked more hours, "tightened their belt", borrowed money from relatives, or asked relatives to sponsor the treatments. A woman who depleted all of her family resource on anti-viral drugs and started borrowing from her extended family to pay for his medications said, "I give him the best treatment I can. He has to take anti-viral drugs that cost 4,000 Bath a month even though we don't have enough money and don't make it month to month. I want him to be healthy again. My relatives said I rather save that money for my children's food. What can I do? I can't do that and let him die. I have to find a way." Another woman exhausted all of family saving when her husband was very sick. She is the only breadwinner and starting working more hours to support the family and pay for his medications. "We have expenses every day, I have to work and make money every day."

Connection to family/others. Because of fear of being shunned and not wanting to worry relatives or hurt their feeling, women often disconnected or kept their distance from their family. A woman who disconnected with her family because of her fear of being shunned said, "I am afraid they will shun me. I did not reveal this to anyone…even family. I cut my self off from them. I don't have family and relatives otherwise; they will sell me out to the public. I heard them bad mouth others who have HIV. I listened to them and thought…oh no…I should keep it to myself, so I did."

Another woman decided to stay away from the family since her husband had wasting syndrome. "We keep it to ourselves. None of us tell our family back there. We no longer go to the hometown to visit our family like before. He is ashamed of his appearance. He is afraid they will ask what is wrong with him."

A youngest daughter left her family to marry a husband from another region and moved far away from home to live with his family. He was sick after they married two years and she provided care for him for months before he was diagnosed with HIV. She did not disclose her HIV status to her family. She only talked to her mother on the phone, but never went to visit her after she learned about her HIV infection, because did not want her mother to see her sadness. "I don't let my mother know how sad I am. Only she saw me taking care of my husband for months, she already cried a lot. She feels sorry for me and wonders why I have to come across something like this….taking care of sick husband for a long time, dealing with a troublesome mother in law who doesn't understand me"

Women also lost connection with others such as co-workers and friends. One HIV negative woman isolated herself from others at work because they found out that her husband had HIV. "I thought my coworkers don't want to socialize with me….I don't want to work there anymore, but I don't have a choice…Sometimes, I don't want to join in the social activities at work. I know that many people know and I think they must think that I am infected and look at me negatively. I assume they don't want to socialize with me."

Time for self/children. A woman felt that she does not have time for herself to do whatever she pleases like other women. "Other wives have time to walk around the neighborhood, play card, and get together and gossip. Why they can do, but I can't. I can't even go out for an hour without him calls me to come back. I work in a different market; he still calls to check on me. Now, it is a little bit better. He let me out sometimes."

Another woman said, "He calls for me if I am not in his sight…many times a day. Since he is sick, he always does that. He said it is lonely. Where ever he is, he has to see me around."

A woman shared her story, "Now I don't have time to read a book. I loose my personal time…Before, I love to go a salon, shopping for cloth in the mall, and read. I love to read a book. I stand in a bookstore for hours. But all those are gone since he is sick. He knows that I love to go to a salon. At that time, he started to feel sick, but he drove me there and told me to meet him at the car about an hour. I thought he wandered around in the mall like he always does, but no he didn't. He slept in the car waiting for me while I have my hair done….I don't know ….(cried). I never went to a salon again. I sympathized with him that he had to sleep in the car waiting for me. I don't want to see him waiting alone. Since then I never asked him to do anything I want. I used to be like—let's eat out this evening. We often go out for dinner. Now my husband's health get worse, he had to watch what he eats and he can only had a couple bites because he was tired. After that, we never eat out since."

A woman was sad when she realized how little time she spent with her daughter when she was busy working and giving care to her husband. She had not seen her daughter for three days despite living in the same house. She described "One time, I went to the bathroom early morning. She stood on the stair, peeked at the bathroom door from there, waiting for me to open the bathroom door to say hi, I am going to school. I felt my heart dropped. I was terribly sorry for my daughter. I don't have time for her. I came home, she was already in bed. Three days in a row… I thought that is my kid. My heart felt…I don't know how to explain the feeling, pity (trembling voice). She must want to talk to me badly."

Dreams/goals. Women, when they get married, often dream about what their family would be like and what they want to do for their family. HIV infection cut their married life short. A HIV negative woman talked about her family, "Our family was having a bright future. It was only the beginning of our married life and was going so well." HIV shattered not only the family's future; it also destroyed family goals and dreams, especially in HIV positive women.

For the nine wives who were HIV positive, after having contracted HIV from their husbands, they acknowledged that they were both dying. They realized that they would not be able to accomplish their goals or make their dreams come true. A woman said, "When I see other families, I felt sorry for myself. I can't do what they can do. I used to dream about having this and that. Now I don't. I don't know what I will have that for. I give up my hope." Another newlywed woman described her disappointment, "I want to have a car, a house, a kid. Now I don't wish that high. I used to hope for those things. I worked very hard to get what I want. My dream was shattered. Now I don't have a chance to make them happen."

A HIV positive woman who was living with her husband's family tearfully described her lost dreams. The couple had been married for two years and he was working toward his baccalaureate degree before he got sick. "Before, I think ahead that we will have kids. After he graduates, we will have our own place where it is closer to my family, then buy a car or do other things, but now we can't do all those things. We have to think that we must use that money for our treatments. We have to have money to care for ourselves."

As a parent, women want their children to have a good life and good education. A HIV positive woman who had learned that she and her husband had HIV for 5 years said, "If we die before our children graduate, it will be very unfortunate. My children will not get the highest education and have a good job I want them to have." Another HIV positive woman who had children said that they were sad that they will not have an opportunity to raise their children and see them grown up.

Another woman was sad by the fact that she won't be able to accomplish her goal of giving things to her parents to express her gratitude to them for raising her. "I think to myself, if I die, my parents…until now I haven't helped my family to the best of my ability. I haven't given them as much as I want to. I thought I want to give them many things…I will do this and that for them, saving money for them, but I haven't done it yet. If I die, it means that all my life, I haven't done anything for my partners and grandparents, not to the fullest. What a pity. Whatever I want to do for them, I have to worry about this disease I have."

Even for HIV negative women, life's goals and dreams were very different after learning of their husband's HIV infection. "My life goal has totally changed. I don't dare think about it at all. I don't dare to plan my future. At the beginning, we planed to have a baby right after we got married. His mother told us to have many kids. They wanted lots of grandchildren. We planed to have 5 to 6 children. His parents really wanted to see our children."

Reproductive opportunity. HIV positive women were not encouraged by health care providers to get pregnant because of the child's increased risk for infection and the fact that the child of HIV positive parents would be orphaned. In this study, one HIV positive woman and one HIV negative woman who wanted to have a baby gave up their reproductive opportunity.

Although not infected by HIV, the HIV negative women gave up thinking about having a baby because she was using condom to prevent HIV transmission from her husband. She said, "I was very sad. Every woman, when they get married, they want to have their own kid, so their life is completed. All of my siblings have their own children. For me...why I have to be so unlucky…If you ask me now, I would say I gave up the thought of having a baby. At the beginning, I cried every night because I know what is my fate and future."

Another newly wed woman who was infected by HIV described her surrender of her desire to have a baby. "When I was sad about not having a baby, my husband comforted me and said it is okay if we don't have children. I used to want to have a baby so badly. I hoped for a wonderful family. Now, I already gave them up and kind of accepted that I will never get what I dreamt of."

Opportunity for treatments. When families were under financial strain, it was the women who shouldered much of the financial burden, many of whom, sacrificed their opportunity to receive their own HIV treatments. A couple, who were both HIV positive, were on the edge of not being able to make it financially because of the husband's illness forcing him to quit his high salary job and work at home. Although the husband had been paying for his anti-viral drugs out of his pocket for years, the clinical trial that had paid for his wife's free anti-viral medicine was about to end. The wife was considering the option of quitting anti-viral drugs so her husband could continue to take his drugs because he was sicker than her and he was still functioning as the breadwinner, although at a much lower capacity. She said, "I am afraid that we are not going to make it. Now, we had lots of expenses. It is money I am worrying about. I thought if I do not take the drugs, will I get sick? I am afraid that I will not have money to buy the drugs. It is more likely that could happen, because my husband pays a lot for his drugs. If I have to pay for the drug too, we will not make it. I thought that if I quit taking the drugs, will I survive. I plan to take herbal medicines and keep myself healthy. We can't afford it...we can't make it. We will loose our house."

Another woman skipped her follow up visit with the doctor who treated her muscle pain, when her husband need to see the doctor for HIV treatment, because they did not have enough money to pay for both visits. Two women, whose HIV status was unknown, ignored the opportunity to get HIV tested and properly treated because they did not have enough financial resources to do that and were too busy working to support the family while their husbands were sick.

Way of life. Women gave up their previous lives or the lives they expected to have when they were married. They never expected the present life they had. A HIV negative woman who became a breadwinner of her family after her husband's health declined and got sick for the first time stated, "Look at others, they have time for shopping. My brother and his wife, I saw them dressed nicely walking in the mall when I went to pay my phone bill. I went there and had to hurry back because I had to go back to work. This is not right. Before, I was not in this position, but now I have to be here. It is like...my life is falling down."

Women who were housewives taking care of their families at home, gave up their comfortable life and took on multiple roles of breadwinner, a caregiver, and family leader and began to do things they did not want to do or ever thought of having to do. A woman who used to be a housewife recounted how her life had changed. "It has changed in the way that I got to go to work…..Before, I don't have to do anything, but now I have to do everything, like…driving around. Before I thought I never want to drive, but he told me I have to learn how to drive and I thought why? Do I have to learn? Because he can drive so why do I have to drive? I don't have responsibility of driving. That is what I thought."

Another woman who was a housewife of a husband who had a mechanic shop described how her life changed after her husband's sickness. He quit working and she became the breadwinner. "Previously, my life was simple. I don't know how to drive. I only help him a little bit at home, fixing a part and sometime running out to buy things for him. That's it, easy tasks, not very tiresome. Someday, I am lazy, I would tell him I don't want to go. But nowadays I can't. If I am lazy, I have to go out to work anyway. If I am tired, I have to go. I have to go to the market even when I don't feel good myself. In the past, I can refuse, but now I can't. I have to responsible for everything. They all are on my shoulder."

A HIV positive woman missed her life when she was able to work. Now she became sick and had to stay at home. And another woman missed her life when the family was happy and lived comfortably. She explained what it was like for her before he was sick. "… if he is all right, if he is not sick, our life would have been better than this. I wouldn't have to be suffered. If he is alright, if he is normal, if he can do things, I won't have a hard time. When he is fine, when he's healthy, he worked hard. He is a very hardworking man. I don't have to be troubled. I don't have to get tired. I don't have to do nothing. He will take care of everything. I don't have to do a thing. He will take care of it. He worked and came back late at night. No matter how late it is, he brought food for the children… everything. Now, I take care of everything. I work for the family and for him. I have to do everything".

Dying together. When the participants first learned of their husband's HIV status, every woman in this study perceived that she was must also be HIV positive. Once they were tested, however, nine women in the sample discovered that they were not infected. So, whereas they accepted their fate of probably having HIV at the beginning, when they learned that they were not infected, most were happy about it. Most made a couple's mutual agreement to protect the wives from sexual transmission by using condoms. As such, most husbands did not want their wives to get infected and die of AIDS with him.

However, there was a sub-category of data from three HIV negative participants who held the belief that dying together was preferable to their husband dying alone and did not take prevention measures like the other HIV negative women in the study. One of these HIV negative women later became HIV positive. Dying together referred to an agreement these couples made when they first learned that their husband had HIV and these three women did not waiver from that initial agreement. These three women were young and had no children. They had a strong sense of sympathy, love, and connection with their husbands, so they wanted to die with him by taking a risk of contracting HIV. These women perceived that not shunning him was a part of their caregiving and if dying together was what it took for her to show him that she did not shun him, then that was acceptable to her. They did not perceive it as killing themselves, but that it was normal for a wife of a husband living with HIV to also be infected by HIV and to die together.

These three women made a decision early that they want to die with their husband. Even when two of the women found out later that they were not infected, they did not change their thoughts about dying together. These women gave up their chance to survive, and believed that sacrificing their lives by putting themselves at risk was both a part of their wifely duties and a part of good caregiving.

Because PLWA's often feel vulnerable to discrimination and rejection from others, including their own wives, these women perceived that they would hurt their husband's feelings if they asked their husband to use a condom in order to protect themselves. They perceived that their husbands would feel that he was alienated and shunned by his own wife who was the one he loved and was supposed to stand by his side.

One woman, after 2 years of unprotected sexual relations with her HIV positive husband of two years, discovered during a screening test for a job application that she was HIV negative. She explained that moment, "We have been living together for more than two years, I thought that if he was infected, I must be infected too because it has been two years, but I didn't have a test….My test shows that I was okay, not infected. I was happy but wondered whether I am so lucky or if my husband lied that he has HIV, because he showed me his lab result paper and I don't really know how to read it. Once I learn that I was not infected, I was very happy; like I was born again. You must understand…a person who was waiting to die…there was a grief in my mind." That was four years ago. Since then, she still has not started protecting herself. She believed that protecting herself by using a condom was hurtful to her husband and made him feel lonely that he had AIDS alone. She explained why she did not protect herself from contracting HIV.

"I thought that since he was HIV positive, I must be too and only that the positive result doesn't show yet. My friend asked me why I didn't protect myself at that time. I said to her—what do you want me to do? You want me to get up and say I want to protect myself, don't you? How about him? His feelings, he must feel really bad. His background…he has the issues about his family. He lost 4 of his family members at the same time, only he survived. One wouldn't understand…actually…he wouldn't understand that now that I am not infected, I'm going to protect myself. It is like he would be alone then. Besides, he is a thin-skinned person (bashful). So, I thought it is not that I am not infected, just that the test hasn't found it yet. That's how I think. I think he can't handle it concerning his mental state. Also, I viewed that we already took the same road together. I thought like that. So here I am."

She gave the example how much her husband was depressed when she found out she was HIV negative. "I teased him that -- see! A bad person like you couldn't attack a good person like me. I was kidding him, but I already made up my mind to accept that I will die with him. Only hearing me teased, he was very sad and down. So, I said—don't worry, it is just that they haven't been able to find the virus yet. I am infected like you. Look! I never shun you at all. Here, I am still with you."

Another HIV negative woman had thought about dying with her husband. Although her husband insisted on using a condom after the diagnosis, she was not that concerned about being infected. She described her first thoughts when her husband was told about the HIV diagnosis. "I thought to myself…I thought…my husband must think I am not infected, but I am infected. I must die alone. I thought about that in my heart, in my heart, but he never said that. I myself thought like that. I told his doctor you shouldn't tell him that I am not infected. You better say that I also am infected. My feeling is…I am afraid that he thinks he will be alone, he will be lonely, or that I will leave him…something like that." This woman had a special connection with her husband and was willing to die with her husband. "To tell you the truth, if he goes, I must go too. Sometimes I told him - don't protect me anymore honey. Let it affect me too - like I am okay to get infected. He said, No. I am glad that you are not infected. He was glad that he didn't commit a sin on me. He didn't leave me his sin. I told him don't say that, I told you don't say that. I told you that we are dying together and I really mean dying together. I don't want to use protection, but he still uses it. He said please protect yourself, please. He is concerned about me. It is good that I am not infected. But my feeling, being infected or not being infected is the same, because I can't live without him."

These women had the idea that it is okay for them to get infected because it is a consequence of the couple's agreement to die of AIDS together. One of the women said "I already made up my mind, it is okay if I am infected". Part of the reasoning behind couples deciding not to use condoms to protect the wives was because they assumed that the wives were already infected, so it did not matter if they did use one or not. Another reason the participants stated they did not use condoms was because their husbands did not like to use a condom as it made him feel less sensitive and he did not enjoy sex as much using it. "Every time I sleep with him, I am not happy because I am afraid to be infected. The reason I sleep with him is because I sympathize with him."

Although these three women accepted the fact that they could get infected, and rationalized the reasons for not using condoms, there was still fear of transmission. The same woman explained, "If you ask me if whether I am scared, I am scared- scared of transmission. But I also think that it is okay to be infected because I did make a decision to stay with him." These women experienced much conflict regarding this topic of what it meant to be good wife, and yet, these three women believed that "dying together" was preferably to protecting oneself from transmission.

Enduring the Struggle

Women sacrificed their well-being to stay with their husband, and, as a result, endured multiple day-to-day struggles in the process. There were four categories related to the emotional struggle women endured: fear of sickness and death, public/private self, keeping the secret, and living with a time bomb.

Fear of sickness and death. It was terrifying for a woman to think about the time when she or her husband would become sick and die. If a HIV positive woman was asymptomatic, she had fear of getting sick or developing HIV related symptoms. A woman said, "...worry. I'm very worried. I don't know when I am going to get sick. When am I going to have the symptoms? When is my body going to get weak?"

A husband's deteriorating health status signaled he was entering a terminal stage of the illness. One woman, terrified when her husband was so sick that she thought he would die, described, "I was scared that my husband was going to die. I lit a candle and prayed to sacred spirits to save his life. I prayed asking every God to help him."

Some women dreaded their husband's imminent death, because they did not want the loss of companionship and did not want to be left to live with HIV and/or raise their children alone. For HIV positive women, the death of their husbands would leave them fighting with the disease alone. "I don't want him to die and leave me and my children to deal with HIV alone. Having him here to be my courage is good."

Fear of death was not constantly present in their minds, but it increased when seeing other AIDS patients who were very sick at the HIV clinic or else where. A HIV negative woman went to a neighbor's funeral who died of AIDS and explained her fear, "Oh… you know, my heart, my heart is very disheartened. When I saw others die, I thought about it…that someday my husband must go (die) like them. I thought about it a lot. I came home and couldn't sleep. My only thought is that I don't want him to die. It is the only thing in my mind right now. To be honest, I don't want him to die. I can't accept that. Something else I can accept, but not this. I always pray."

Fear of sickness and death increased over time. A woman described her fear of her husband's death, "I am afraid because years had passed. The more time passes the more I fear. It is like a glass full of water. As time passed, water is decreasing every day. I am afraid of that day. The day the water is at the lowest level. I am fearful of that day."

For some women, death itself did not create their fear, but the painful, suffering, and unsightly process of dying did. A HIV negative woman prayed for her husband's good death because she watched her brother die painfully from AIDS, "I pray every day that he will not be like my brother. If he is going to die, let him die easy without suffering. I only ask one thing that he does not suffer and is in no pain. Sooner or later he will die anyway, only if he die peacefully." Another woman prayed for her husband as, "if he is going to die, let him die without suffering. If he is going to live, let him get better, not make both him and me suffer."

Some women did not care much about their own death, but rather they were more concerned about leaving their children to grow up without them. As stated by one HIV positive woman, "I will be dying for sure. Death, I'm not worried about it. Everybody's got to die, every single one of us. But I am worried about my children. I am scared that when I am gone who is going to take care of them."

Because of their fear of sickness and death, some women refused to think about or talk about it. They were too terrified to think about the terminal stage of HIV. They perceived that it would not come soon; therefore they did not plan what to do when the husband was terminally ill. "I don't want to talk about that time. It makes my heart sink."

Public/private self. All of the women in this study tried to hide their private thoughts and feelings about their situation and presented another self to the public. According to them, they did this in order to protect others from feeling hurt or worry about them, to help others feel secured or feel that they can rely on them, to protect themselves from being shunned and scorned by society, and to better conceal her secret. The contradictions evident in this public/private presentation included: I am fine/I am tired; I am happy/I am sad; I am surviving/I am suffering; I am strong/I am discouraged; I am grieving/I accept it; I am brave/I am afraid. Some woman shared their private self with their husband, but some keep their private self completely within themselves.

One HIV negative woman who kept her private self from her family said that she did not let them know that her husband is sick with HIV because she did not want them to worry about her. She said, "I think I should accept what I chose (to live with husband), I don't want others to feel that I am sad or I cry. Then my mother will be unhappy because of me. Did I sit down and cry every day because my husband is sick. Was I tired? Did I look exhausted going to work? No, I never did that. Every morning, I said-good morning mom, are you hungry, what do you want to eat today; I will go out to buy it for you. I never look sad when I am with them. I never let my family know how much suffering I have…When my husband was very sick, we hug each other and cried, but never in front of anybody."

Another woman did not share her private self even with her husband. She worried about her husband's health and the end of his life, and tried to hide her worry from him. She said "I won't let him know about what I think or worry about. I don't want to hurt his feelings. I am afraid he will feel depressed…When he was very sick the last time, I was very down, didn't want to do anything. I went out and sat on the river bank crying alone and spoke to myself to let it out. I never shared with him that I am suffering or sad. I don't want him to worry. I want him to be free of stress. When I am with him, I am always happy and joyful. If I am stressed, I will go out of the house for a while, and then come back. "

Some women presented their emotional strength to the public so that their husbands and others felt secured or felt that they can rely on them. A woman said, "My parents don't know about this. I always make them think that I am (emotionally) strong, something like that. I must present myself that I am okay all the time. So that when my parents need help, they will come to me for help…like… taking them to the doctor. They want me to take them because they can trust me." Another woman's public self gave her husband confidence to fight the disease. She explained, "I must make myself to be a person he can rely on. I can't be in tears every time things go wrong. It will shake him. I must be strong as if anything happens I can help him get through."

Presenting this public self made these women feel isolated and alone because they could not share their thoughts and feelings. Thus, they did not receive the help and support they needed from others because other people did not know how desperate their situations were. One woman felt totally alone and only had herself to cry with, "I go to bed and cry myself to sleep. I only let it out by myself."

Another reason for creating and presenting a public self was to protect themselves from being shunned and scorned by society. A woman was always supposed to put on a happy face when she was with friends, especially those who did not know about her husband's diagnosis. She noted, "My friends said that my husband is sick, but I am still happy and able to laugh. I thought it is no use to let they see my sadness. If they saw me crying because my husband is dying of AIDS, they will shun me and think it serves me right that my husband is dying of AIDS."

Sometimes, woman put on a happy face to the public in order to better conceal her secret. A HIV positive woman who was perceived by her friends that she was able to cope well with her husband illness, said, "…my friends saw me as a happy lady. How can I tell them that actually I have many problems in my life? If I tell them that I am battling with AIDS, will they be able to accept this fact? I am like a counselor for my younger friends. They will consult me with this and that, but I can't consult with anyone about my life. I don't dare speak out."

Keeping the secret. Sharing the HIV secret with husbands and keeping it to themselves were very difficult emotional work. It was a heavy emotional responsibility for women and these data revealed this as an embedded aspect of the caregiver role. Women cannot talk about their struggling experiences or share their story with anyone else because of feelings of shame and fear of discrimination. A HIV positive woman who lived with her husband's family far away from her own family wanted to share with her family about her ordeal, but she could not; she could only keep it to herself, "I am sad, I am suffering, but I don't want to say it. I don't know whom I will say it to. I can't tell my mother. She calls very often. I want to tell her but I don't dare. I want to, but I don't want my family to know, my mother either."

Having no one to talk to during difficult times, one participant talked about how she dealt with her stress. "I just cry…drink and then cry. Tomorrow I will become a new person, can work and fight again. But I have to cry, because my heart is drowning in my tears. I have no one to talk to; I don't know whom I can talk to…If I talk to someone, he/she may feel that it serves me right, or look at us negatively." Keeping the secret was an act of protection for her husband, herself, and her family; protection from being shunned by others or protecting others' feelings from being hurt.

For some women, it was frustrating keeping the secret. A HIV negative wife had been keeping the diagnosis secret about her husband for 7 years. He did not seek treatment until he developed HIV related symptoms. She described her relief of not having to keep the secret all to herself anymore. "I admit that I was happy that his doctor knows (that he has HIV), because I never talked to anyone about it since I learned about it (7 years ago). I was having a hard time. The fact that you keep someone's secret, and don't tell anyone, it was bothering me. He was able to tell me his secret, and I keep it for him, but what about me. I felt worried and couldn't let anyone know. Now, I have doctors and nurses to talk to about it. If I talk about it with others, they may shun me… When we come to see the doctor here, it helps. At least the doctor knows. The secret I have been keeping inside, now it is not a secret anymore. Although his family doesn't know, at least the doctor knows and I feel good about that."

Silent knowing is a sub-category of keeping the secret. Silent knowing referred to the action of knowing the truth, but not being able to tell. One husband had a gall bladder operation and had a difficult recovery because of complication from his HIV infection. Living with his extended family, his wife was struggling to make his parents understand his situation without exposing him. "These past two weeks, he has been in bed…very sick. His father often asked what was wrong with him. I had to tell his parents I didn't know. Only the two of us knew. We strictly keep it secret. We don't want them to know. So, his father wonders why he never got better. I can only say the doctor was trying to investigate the problem and was adjusting his medication, but I didn't dare to tell him what his son had. We were afraid that he wouldn't be able to accept the truth…Sometimes he (husband) was in a very bad shape, having chest pain, being very sick and not able to get up from bed. I didn't know what to do. But, we concealed it from his parents. They saw their son as being lazy. His house is a retail store. His sister accused him as a lazy son who let his elderly parents work alone with out help. I can't say to her what he has (trembling voice). I can only defend him...uhm…may be he will come down and help when he feels better." This participant sympathized for her husband and did not like it that he was being wrongly accused. She wanted to defend him, but felt it was too dangerous to do so. It is interesting to note that it was more acceptable to be judged lazy, than to be discovered as having HIV. "Nobody knows (he has HIV), they only know he is sick and recovering from the operation. They think he is lazy and not trying to recover himself. They see him as pretending to be sick and weak. They said he does not act like a man; that he doesn't have a masculine heart at all. I told my husband to be patient because they don't know the truth. I think there will be one day that I loose my patience to see my husband being bullied. I may tell them then."

Another example was of an HIV negative woman who was married for seven years, but did not yet have a baby. She was pregnant, but aborted naturally. Three months later, she found out that her husband had HIV. Her husband's parents accused her of being infertile; she was, in fact, using a condom to protect herself from contracting HIV from her husband during those for seven years. She described her experience of being blamed of not getting pregnant and not being able to defend herself or tell the truth about why she cannot get pregnant "They think that there is something wrong with me. Everybody sees it as me, because I was able to get pregnant once. They are confident that their son is not infertile. So, they blame it on me; my uterus is not strong enough to keep the baby. They complain about me. I say....okay it is my fault. Sometimes I thought, maybe his parents want him to have another wife, because I have not yet had a baby after seven years. Other relatives already have many....My relatives ask me very often why I don't go see a fertility doctor....I have to avoid them or lie to them. I can't tell anybody, I am so frustrated, but I can't do anything."

Women intended to keep silent until they were no longer able to keep the secret or until other people found the truth themselves. A woman noted, "I think someday they will know. Definitely, they will know, but when? I don't know."

There is another aspect of silent knowing. Sometimes, family, friends, co-workers, or relatives learned about the HIV diagnosis because of how they or their husbands' looked, such as the wasting syndrome specific to AIDS, but these friends and colleagues avoided saying it to the PLWA or his wife that they knew about it being AIDS. A woman who lived with her extended family said, "I think people at my house know, but they don't say anything. I don't know...they are like...better not to say...My mother and sister know, but they never say thing to hurt me." There was a mutual silent knowing between them. They avoided talking about it and did not want to hurt the women and their husband's feelings or make it uncomfortable for them.

Living with a time bomb. This is a category that represented an aspect of the women's lives who were waiting for their own death or the death of their husbands as they wondered how much time they or their husbands had left. Women thought of their life and the time they had left as if it was set by an invisible time clock, the moment they learned that they or their husband was infected by HIV. They realized that life stopped moving forward at that point, and was counting backward as the clock was ticking every second, minute, hour, day, month, and year until the time of death. A women said, "…it is bad. We are counting time backward only. I don't know what to do. I can't plan on the future."

The primary nature of HIV disease is uncertainty. The disease can progress at different rates for different people. Women associated their life and their husband's life as waiting for death without knowing when it would come. Hence, they could not do things that involved long term commitment.

A HIV positive woman who had been diagnosed for 10 years described her feelings. "After 10 years, my life was not better than it was when I look back. I worked, but instead of having lots of saving, I had to spend money for treatments. I couldn't save money for my children. I wanted to buy a house but I didn't dare. I am afraid that if I die, my children are still very young and it will cause problems for them. I did not dare to do anything, but wait for when I will get sick. I always worry when I will die. I dare to do nothing. My husband is sick often, so I always worry about money. I don't have big cash, so I can't do anything. I thought about buying a car, but again was not brave enough. I don't want to have a problem later if I die at that time. I worry about my children. My husband told me to finance our land in our hometown to buy a house in Bangkok, I did not dare. AIDS is pulling me back all the time. I thought my life should go farther than this. It shouldn't have been like this."

All of the women hoped for the longest time that the "time bomb" would not explode so that they could enjoy the rest of their life, finish unfinished business, build financial security for their family, raise children and watch them grown up and be independent. The longer their husbands and they were healthy, the higher the hopes they had for long-term survival. When their health deteriorated and HIV related symptoms occurred, the reality of pending death resurfaced. A HIV negative woman whose husband had been healthy for seven years and had just gotten sick a couple months ago said, "It was normal. I knew that he has HIV. Now I feel bad that he developed symptoms. If he doesn't have any symptom, I feel okay. It is like an old wound and then we scratch it. I already knew that he has HIV, but when the doctor said it again, it is like reminding me again that he won't stay with me long. I did not think about it before. I forgot about it, totally forgot"

What these women wanted the most was a little more time before the unavoidable death. Some women prayed for a blessing that HIV disease would not progress quickly and the terminal stage would arrive later, rather than sooner, allowing their husbands or themselves to live as long as possible. Women who had children wanted to live with their children as long as possible. A woman said, "I hope I live long. When I first leaned about it, I hoped to live only 6-7 years. But now I am there, I hope for a little bit further. I further hope to live until my son finishes school. At that point I only want him to mature enough to be able to accept things." None of the women thought that the time she had in the past was enough. They always hoped for more time even though it was not likely to happen. A woman said, "I told my husband that he could live another twenty years. I honestly think he certainly could live for up to ten years. Now he is 39, then he will be 49. That is what I thought. I said, don't worry, more than 10 years that he will live, because he has already lived through seven years."

Another woman desperately hoped for more time to raise their children, "...If something happens to us, our children are so young. We wouldn't ask for anything for the rest of our life. We just ask for that our children grow up a little bit more. And we will never ask for anything else. I think about it everywhere I sweep the street. I think like that, just think that just please give us a little more time for our children to grow up (Crying). Just want our children to be able to survive."

Actions/Interactions: Sacrificed Caregiving

Actions and interactions were the strategic or routine tactics persons use to handle a situation or resolve the problems they encounter. Actions/interactions are altered by the intervening conditions (Strauss & Corbin, 1998). In this study, the actions/interactions that women used to handle their situation involved sacrificing what they had in order to give care to their HIV infected husband. This sacrificed caregiving was performed alone by the women and was hidden from the eyes of the public. The set of actions/interactions of the sacrificed caregiving composed of five processes: giving care, preparing for death, taking on multiple responsibilities, taking risks of contracting HIV infection, and getting through.

Giving Care

The process of giving care consists of three sub-categories: instrumental caregiving, assigning husband a sick identity, and redefining well-being. Each sub-category is elaborated below.

Instrumental caregiving. Instrumental caregiving referred to the actions women used in providing care to their husband at home, i.e. what the women actually did in the performance of this care. All of the women in this study were primary caregivers to their husbands. However, some women received assistance in caregiving. Other family members, such as mothers or sisters, would sometimes support the caregiving at home or when the husbands were hospitalized. Women managed symptoms and provided care based on their previous experience from their husband's earlier illness episodes or from providing care to other family members. Caregiving usually started as early as learning about the HIV diagnosis. Over the course of HIV disease, instrumental caregiving activities women performed were of two types: emotional care and physical care.

Emotional care the women gave involved providing support, primarily in the form of encouragement. Most husbands were devastated and discouraged when they first learned they had HIV. Giving encouragement included holding hands, hugging, and giving assurances that he will not be left were the most important psychological activities women gave early in the diagnosis. A woman trying to encourage her husband immediately after his doctor told him that he was HIV positive said "I comforted him. I told him--what is meant to happen will happen. If you take good care of yourself, you will live a long time. Whatever happens, I will be with you and die with you. I won't leave you. No matter what I won't leave you." Most women believed that giving encouragement was important because it helped their husbands to have the emotional strength to fight the disease and in doing so, they would to live longer. A woman encouraged her husband to fight when he gave up, "He lost his courage. He quit taking the drugs because he gave up hope. He didn't want to do anything. He said he was ready to die. I told him to think about our son. I said you can't give up like this. Our son is too young. I told him to get up and fight again."

Other emotional care strategies included providing companionship, protecting one's husband from emotional harm, and minimizing emotional distress. One woman described her companionship as, "He feels lonely and fearful of the future. He is scared of death. He said he lives until today because he has me. Where ever he goes, I accompany him. I'm always with him." Another woman protected her husband from hearing others' discriminatory comments. "Our neighbors keep telling us that person has AIDS, this person has AIDS. I don't want him to hear that they shun people who have AIDS. He will be more stressed. When they talked about AIDS, I would argue—AIDS is a natural disease. Whatever disease people have, they all die anyway. So they should be quiet." A woman tried to help their husband who was emotionally distressed by diverting his attention from AIDS. She said "After being diagnosed, he quit working—he was down, so I invited him to help me work, selling stuff. He has been gradually better since then, until the last time he was ill."

In addition to providing emotional care, women spent time and energy into their husband's physical care. The activities and intensity of physical care varied depending on the husband's stage of HIV illness and his health condition. For husbands who were in the early stage of HIV infection, physical care focused on monitoring symptoms and changes in health, encouraging health promotion activities (exercising; hygienic dieting), quitting hazardous behaviors (smoking, drinking), balancing activities and rest and preparing and reminding him to take his medications.

Many women mentioned that preparing and reminding husbands to take medications were the major activity. The wives were in charge in preparing and reminding their husbands to take their anti-viral drugs because the husband's tended to forget to take them. "I have to make sure that he takes his medicines on time. Sometimes, he doesn't concern himself about it and it passes medicine time. So I yelled—"take the medicine, come down to take your medicines. Eat your meal before taking them.—I prepared every thing for him. I have to remind him every day. When he goes out to work in the field, I pack his medicines in his food bag and remind him to take them on time."

When the husbands approached the end stage of the disease, their health progressively declined. They grew weaker, were bed-ridden, or had limited functioning because of HIV symptoms related to blindness, fatigue, muscle pain or atrophy, or cognitive/neurological impairment. Therefore, caregiving was more focused on assisting with activities of daily living. The caregiving tasks included bathing, grooming, toileting, food preparing, and medicating.

Often, women were vigilant about the signs of illness, since husbands had a tendency to get sick. A woman said, "I observe him carefully. I keep asking him do you have a headache or are you tired? If he eats less, I ask what happen." Another woman noted, "I told him that he must tell me when he doesn't feel good. I always remind him…if you feel something is wrong, you have to tell me." Previous experience with his illnesses taught women to be alert of his next illness episode.

Besides closely monitoring the symptoms, women also managed them. For minor symptoms, such as fever, headache, diarrhea, dermatitis, oral thrush, or herpes, women initially managed the symptoms using over-the-counter medicines or herbal medicines. A woman described, "My husband doesn't like to tell me when he has something wrong (symptoms), but I observe him, so that I know he has symptoms. Then I ask my sister (she is a nurse) about the medications and I buy them for him." The same woman gave an example of how she managed his symptoms, "If he has fever, he will get worse. So when he starts having fevers, I quickly give him fever reducer pills. My house is like a drugstore. I bought lots of medications for all kind of symptoms. I have them all…When he had any symptoms, he can take it right away. It is that…I was scared that he will be very sick"

If they were not cured or if major symptoms occurred, women encouraged their husband to seek medical treatments from the doctor. Some husbands avoided the doctor because of shame, and when they did go, they often did not reveal their HIV status to the doctor. Wives frequently had to take them to the doctor and encourage them to tell the doctor about the HIV infection.

The majority of the women in this study were actively involved in the decision making about their husband's care. They advocated for their husbands in getting the treatment they needed and they encouraged their husbands to reveal the HIV status to their doctors so that the doctor would not waste time investigating the cause of the illness. A woman said that her husband did not disclose his HIV status to the doctor when he first sought the treatment for his itchy skin. She described, "The dermatologist ordered a blood test for him. I previously told my husband –you got to tell the doctor. If you are shy, whisper it to him. Nope, he did not tell the doctor. I looked at his lab paper, he wasn't tested for HIV. When is the doctor going to know that he has HIV? I told him you have to open up your mind and accept the truth. I came and talked to the nurse here, she said take him here. I had to grab him out from the dermatologist clinic and took him here to the HIV clinic."

In addition to direct physical care, there were other caregiving tasks women performed, including: taking husband to the doctor, managing health insurance, and searching for and securing health care.

Several women have taken their husbands to many health care facilities with high hopes for a cure. They were manipulated into buying many remedies that falsely claimed to treat or cure AIDS. One woman had been searching for health care for her husband before entering into the health care system her husband is now in. She noted, "…I took him everywhere. Wherever someone told me they have medications for AIDS, I went there, but it did not help him get better."

Many women had to search for the right place to get HIV treatment because of the gaps in quality of care among the government health care institutions. Anti-viral medications were not prescribed in every government hospital around the country. Most women and their husbands had to search and seek care at the right place to gain access to anti-viral medications with affordable prices. Women tried to search for the best health care for their husbands. They tried to get access to an HIV/AIDS specialist and to anti-viral medications in order to help their husbands get better, to prolong his life, or to, at least, allow him to die without suffering. A woman recapped the story of her searching for quality care when her husband first sought care in their hometown. "He had a chest x-ray at the clinic and the doctor said his lung had a spot and he suspected that he may have TB. So he suggested we go to the hospital to check for TB. The hospital did not treat him, not one bit. I had all the paperwork done, but they never examined him. I could tell that if my husband stays at that hospital, he would die. The doctor did nothing for him, only gave him fever reliever, no other medications. Even when I showed him the x-ray film, he did not do anything. I told him I am willing to pay out of my pocket if only he would treat him as the doctor at the clinic wrote in the referral paper. He read it and then put it back, but did nothing, but gave me pain reliever. I couldn't stand it. So, I called his brother (in Bangkok) and told him I wanted to get treatment. Before that we went to a clinic that turned out to be a scam. They charged us even though they did not charge before when we went there. I agreed to pay, but they charged us more and more and the drug had no effect. I called his brother and he took us here. At first the doctor here said, any hospital treats patients the same way, why don't you go back to your hospital in your city. I told him, I am not going to go back. That hospital gave me pain reducer. Will my husband be cured? I am willing to pay. I am not a rich person, but I will find money to pay for his treatment. His brother helped working through the system, until we ended up here. I said to my husband—you are lucky that you found this doctor."

In addition to having to search for the place to get treatment, women and their husbands must be able to financially secure their care. With the public health insurance regulations, people were required to receive care at the government hospital located in the city they live. One of the HIV positive couples had to move from Bangkok, where they work, back to their city to continue their HIV care because they could no longer afford to pay the medical bills out of pocket. They had to leave the best care they had to accept less quality of care in their hometown. A woman expressed her worry, "Those hospital, I don't know how they treated AIDS people, but anybody who went there, they all died. My relative has just died. He learned that he had it four months ago. He was in the hospital and given only IV and fever reliever. They treated nothing at all. I'm fearful for my husband, but we have no choice, because we don't have money."

Assigning husband a sick identity. Women viewed their husband as a sick person and assigned them a new identity as a sick person once he was diagnosed with HIV. No matter what stage of the disease he was in, he was perceived as being a sick person who needed special attention and care, needed to rest more than normal people, and had to limit doing normal activities, such as working. Sick identity included being viewed as more vulnerable, sensitive, irritated, and demanding special companionship and attention.

Woman perceived that a person sick with HIV should receive special treatment from their caregivers and others because they were vulnerable and had to conserve their physical and emotional strength. Additionally, they should be forgiven or should not be reminded of their actions or behaviors which resulted in HIV disease.

A woman treated her husband differently after he was diagnosed "I constantly worry about him. I'm afraid that his health will get worse. I don't let him work. I do everything. I do not allow him to do things he used to. Since he was diagnosed, I didn't let him touch a thing. Never. I did them all by myself. I have strength to do it. I make money to buy drugs to treat him. I don't want him to worry about anything....since he got sick, I take care of him all the time, I am never far away."

For a number of husbands in this study, being fearful of death, being sick with multiple illnesses, losing independence, being unable to help himself with daily activities resulted in emotional and behavioral changes, such as being aggressive, picky, demanding, annoying, selfish, unreasonable, insensitive, jealous, and emotionally irritable. Women accepted the situation silently with an understanding of their husbands' changed emotional status; however, they felt discouraged by it also.

A woman explained her husband's emotional change as "…He is likely to have a quick temper and be in a bad mood. It is like he used to be able to help himself, but now it is not like that. He became dependent, so he is frustrated, easily annoyed and easily angry. He said things he shouldn't say...At that moment, I thought he was thinking about himself, his future, in other words, feeling afraid of his own death."

Because husbands were given an identity of a sick person, women privileged their husbands and they had to endure the results of that privilege. All of the women in this study justified this behavior as being an aspect of his illness, and were able to forgive him for his bad behaviors. A woman, who was dealing with her husband frequently saying hurtful words, said, "... I listened and kept silent. I never argued back at him. I let him say whatever he wanted. After a while, he thought about it, then he behaved himself. He will be very good to me again." Another woman described how she dealt with her husband's emotional irritation, "I have to be very patient…very patient. It is that…you can't say anything that may hurt him emotionally…he is very sensitive. I can't say things I say to normal people. I must calm myself down. I have to control myself not to be easily shaken."

Redefining well-being. Unlike other life-threatening diseases, AIDS is an unpredictable disease in its trajectory and progression. PLWA's experienced several up and down health conditions due to opportunistic infections. The fact that AIDS is not curable, combined with the uncertainty of the disease, women learned to set lower standards of what it meant to be healthy and redefined well-being for their husbands. Instead of thinking about being cured, they thought about not getting sick; instead of thinking about recovering to a healthy level, they thought about not getting worse; instead of thinking about being able to function normally, they thought about just being able to help himself with activities of daily living.

Standards of well-being varied, depending upon their husband's current state of health. For husbands who were healthy or stable, well-being meant his health did not decline and he was not ill from opportunistic infections. For husbands who were battling with opportunistic infections, well-being meant that they were not getting so bad that they would be unable to regain their health. Husbands who had permanent impairment, such as blindness or were too ill to recover back to their functional state, well-being meant they were able to function doing some activities of daily living. A woman said, "I want him to be cured, but if he can't be cured, I only ask that he can perform his routine. If the illnesses must be with him until he is older, let him not be suffering anymore than he is." Another woman did not expect her husband to return to his healthy state and be able to work after his first illness episode. She redefined his well-being that she could accept. "He can't do anything, but he is alive. He is like a tree that gives me a cool shadow. He doesn't need to do anything. He is allowed to just stand still over there, but do not get sick…Take the medications on time and do not get sick. Take care of himself, so there is no illness, that is enough. That is a blessing."

Preparing for Death

Preparing for death consisted of three aspects: material preparation, wife and children preparation, and caregiving.

Material preparation. Most of the women and their husbands focused on material possessions when preparing for death, such as house and money. Because AIDS treatments were expensive and they will leave their family members behind, saving money was the foremost preparation. For women and their husband who were still healthy, their preparation for death involved saving money for future medical expenses and for their children's future.

HIV positive women and their husbands who were waiting for their death started preparing earlier than those women who were not HIV positive. For most women, building financial security for their children is the most important thing to do before death. A woman said, "I am trying to prepare things for my children. In case when I'm gone, they won't be in trouble." Another woman described the reason that her husband was working very hard, "He works harder to save lots of money because we don't know what our future will be. He doesn't stop working. He said he wants to make money in case we are gone. Our children don't have jobs and they can't rely on others."

Several women were concerned about their children's opportunity for education. A woman said, "I only focus on how I will have enough money to support my children's education." Women who have children expressed their concern about their children's well-being where they will be raised by relatives. They were planning how their children would live by seeking a guardian for their children. Women were trying to find a place for children to live "What I am going to do? His relatives are outside of Bangkok. And my family has many problems too, problems with my parents. I think far ahead like that. If I were gone, it would be hard to ask my parents to take care of my children." Another woman felt relieved when one of her relatives offered to adopt her son.

Wife and children preparation. Knowing that they will have to support themselves, HIV negative women planned and prepared a career or business by going back to career training schools. HIV negative women also prepared themselves to live without their husband. A woman noted, "I don't know that one day he is not with me, how will I live. He always drives me every where I go. Even though I know how to drive, I am scared to drive on the street. When I want to go places, my husband helps me. So, I thought if he is no longer with me, I have to do everything by myself."

Preparing children involved correcting the child's health problems, teaching children to love and care for each other, and disclosing the HIV diagnosis to children.

Caregiving. Besides preparing themselves and their children, some women prepared for how caregiving would proceed once death was close. They planned to seek help when their husbands reached the terminal stage, when caregiving would be more demanding and financial and material resources were depleted. Some, who came from other regions, planned to move back to their hometown to live with parents or relatives when they needed their support and were no longer able to do it themselves.

However, a number of women in this study tended to not discuss the end of life care with their husband, and did not plan for future caregiving or death. Thai cultural belief holds that death generates misfortune for the living and talking about death, while having a sick husband, is avoided because it may be interpreted as leading to impeding death of the husband. Thus, some women did not have a solid plan of where the terminal caregiving would occur, who would help with caregiving, or who would be the caregiver of the wives after the husband's death. They were more likely to let it "just happen" and solve the problems as they arose. A HIV positive woman, who thought her husband would die before her because he was sicker recounted, "We do not talk about that day. I only think that when that day comes, we must take care of each other. If I get sick first, he has to take care of me, but I never ask whether he will do that."

Most of the HIV positive women in this study had wondered about who will care for them when they become sick. An HIV positive woman described, "I thought about it. My husband is sick. He has me taking care of him. When he is gone, okay—it is the end. But if I became sick or if I am in terminal stage, who will care for me? Who will come and get me? Something likes that. I thought far ahead in the future that who will care for me. Nobody. My husband certainly has me when that day comes, because he gets sick before me. Will his parents care for me? No way." Not only HIV positive women worried about her future care, some HIV negative women did to. A woman noted, "I thought if I get infected (from staying with husband), I am afraid I have no one who is very devoted in caring for me the way I care for my husband. When it is my turn, I must have no one." Women perceived that a partner is more devoted in caregiving and more understanding in what the person wants than other family members are.

Some women had in mind who would be their future caregiver, but they had not told them about their HIV infection yet. They just hoped that that person(s) would be willing to care for them when it was time. Some women have not thought about it because the need to be cared for had not arrived yet.

The majority of women expected that their parents would care for them. However, they felt badly about being a burden on their parents. When a women's husband gets sick, often, they receive financial support from his family. But this is not always the case with wives; they do not receive support from their husband's family. One woman anticipated her future caregiving problem, "I am certain my mother would take care of me, but it must be difficult for her…I am worried that if I get sick and lay in bed like him…My mother doesn't have much money. If I get sick, I will be in more trouble than my husband. Besides, I feel bad that I will trouble others. If I die, my parents will be in trouble, because I died of AIDS."

Taking Multiple Responsibilities

This category referred to women assuming multiple roles involving increased responsibilities, including, caregiving, breadwinning, parenting, and family leadership. This category derived from data of the women who did not have strong financial security. Given their limited financial resources, many women took over the responsibility of being the breadwinner when their husband could no longer work and this often resulted in lost income for the family. Women were also responsible for the entire family, such as caring of children, elderly parents, running the household, and taking care of family affairs. A woman described her responsibilities when her husband stayed home sick, "I do not get enough sleep at night because my husband often has a fever or has pain here and there in the middle of the night. I have to massage his legs and sponge him to reduce his fever. And in the morning I wake up and take care of my children, cooking for them, ironing clothes, and walk them to school. I come back and take care of my husband, and then I go to work."

Number and degree of responsibilities increased over the course of illness depending upon the husband's health condition. Overtime, husband's health progressively deteriorated, and finally became terminal. When husbands were asymptomatic, they were able to work and needed minimum caregiving. Women who were housewives were still a housewives and those who were working could still work normally and at the same time giving some caregiving. When husbands reached a symptomatic stage, they got sick on and off and their physical health was in decline. As a result, they missed work or could no longer work, and over time they could no longer work and were bringing in no income. To support the family, their wives assumed the breadwinner role. Women who never worked before started to work, and those who had worked before began to work more hours to earn more to support the family. At the same time, the degree of caregiving responsibilities increased due to the illnesses the husbands had. The burden of taking on multiple responsibilities increased when the husband was hospitalized.

A woman described her responsibilities when her husband was hospitalized “When he was sick I had to go to work and come back and take care of him all the time. When I finished work I came to see him. After I finished sweeping the road around 3-4 pm, I came straight to the hospital, then I came home late at night. And in the morning I had to drive to get the plastic bags. I do everything by myself. I am tired. Sometimes I didn’t get to eat at all because I don’t want to eat at all. I get so tired. I am so discouraged. I have to be responsible for everything at home. Delivery and picking up plastic bags and all. Everything I have to do it by myself.”

As the husbands became terminally ill, they were physically impaired and could no longer help themselves. It became harder for women to provide intensive caregiving, work to support the family and pay the high medical expenses, and take care of the family at the same time. The degree of responsibility varied depending upon support they had from family members. If they lived in an extended family, other family members relieved some of their responsibilities, such as taking care of children, assisting with housework and caregiving. It was more difficult for women who had all they responsibility without help and support from others.

Women who were the caregivers, breadwinner, and family caretaker were more overwhelmed and experienced more stress and physical exhaustion than those who were solely caregivers or who were caregivers and family caretakers. Sometimes, they struggled in fulfilling multiple responsibilities. A woman who worked as a dishwasher/ launderer and lived with a four-year-old son and her husband described the time she was overwhelmed by her responsibilities while caring for a sick husband, "It was very hard. Every thing hit me at the same time. I didn't earn enough money and my husband was sick and had a doctor's appointment coming up. My son was sick and my father, who had been sick for a long time, died."

Women who had strong financial security did not have to work to support the family and could devote their time to providing care to their husbands and take care of the rest of the family. Women with no children were also in a better situation because they did not have responsibility for children.

Taking Risk of HIV Infection

Except for the three women previously discussed, most of the HIV negative women in this study prevented sexual transmission by using condoms. Women who were HIV positive also used condom while having sexual relationship with their husband because the doctor strongly recommended it. To totally avoid the risk of sexual transmission, some couples decided to practice abstinence. One HIV negative woman who was terrified to had sex with her husband, used a strategy to avoid sex, stating "I told him-- you are ill. This (having sex) is like exercising. It will make you feel weary and exhausted. It is like stimulating your disease. He is a very timid person. Because of this reason, he can stop…I told him that this abstinence isn't because of me, it is because it is best for him. I told him I did this for him, so he would be healthy; and the doctor also insists (that he does not have sex). Since we learned about the diagnosis, (having sex) only one time made me feel bad."

One HIV negative women who had been living with her HIV positive husband for seven years described her initial fear of transmission while having sexual relationship with their husband. "If you ask if whether I am afraid. I must say I was scared at first. I was very scared, despite using the condom. Some people say it could rupture. I am afraid that I will be infected, but it is our husband-wife relationship. Of course, I am scared, but this is my husband's needs. I don't know. I guess…okay, but he pick ones with the brand we can trust. So, it is okay. I have been using it since. It became normal. It is only at the beginning that….if we do it many times, it became normal. But when the doctor asked me to have a test, I was scared…scared that I may be already infected."

Besides sexual contact, care-giving activities also put women at some risk for contracting HIV. Most women knew that they should use gloves when contacting body fluids, but few of them wore them when performing that kind of care. None wore masks or gloves to protect themselves for other contagion diseases, such as TB or herpes. The reasons given for not wearing protection included: not wanting the husbands to feel that they were repulsed by them, not considering gloves necessary because not having an open wound, and not practical enough when administering care. However, the most important reason was that they did not want their husband to feel rejected or shunned because they were very sensitive about this issue. One HIV negative woman stated she did not and would not use precaution measures when performing care because she was very concerned about her husband's feeling. This woman did not want to hurt her husband's feelings or making him feel shunned. She explained the reason she never used gloves when performing care, "I am afraid he will feel bad. Sometimes, he says—you are afraid of me. So I don't want him to think like that. I told him—don't you think I'm afraid of getting infected from you." Another woman said, "I am careful, if I don't have any wound, and he doesn't have wound, I don't wear gloves. When I am not sure, I wear gloves. When I bath him, I don't want to show that I am repulsed by him by wearing gloves. And wearing gloves limited my ability to use my hands."

Despite using some of these precautions and knowing somethings about how HIV is transmitted, many women still had doubts about how much effective any of it was in preventing HIV. A woman said, "I thought what I hade done was very safe. When it was time to get an HIV test, my husband did not dare to let me get the test, because he was afraid that I may be accidentally infected. He was afraid I won't be able to accept that. I said it is okay. I must know, so that I can prevent it from spreading. But, I'm never confident that I'm 100% safe."

Some women did not know how to prevent the spread of infection while performing caregiving while other women had better knowledge in protecting herself and others from contracting HIV. Again, there are many implications here for social policy and education.

Getting Through

Getting through referred to the processes women used to get through their struggles while caring for their husband as he was sick and dying, and for nine women, it included learning how to cope with living with HIV herself. Women used a lot of distraction, and tried to focus on something other than HIV, such as work, children, or the tasks they had to do. Women often compared themselves to people less fortunate than themselves, so they would feel better about themselves and have the emotional strength to fight. They tended not to plan for or think about the end, although sometimes, it became very difficult for them to ignore it completely. A few women let their anger out on their husband, while most women calmed themselves by getting out of the situation or crying alone. Some woman employed the strategy of living day by day. "I don't plan anything, because he knew that he is infected and I thought that I was infected too. I just live my life as if I am happy today; don't hope for the future. I spend money I have to eat and play. I don't plan that I will have this and that in the future." Some women tended to make the most of their time left and live life to the fullest. An HIV positive woman who planed to build a family business recounted, "Since I know that I am like this, I stop making plans about what to do for my future, because I won't live long. I start taking good care of my health and living to make myself happy. I am not a prodigal, but if I want to eat expensive food, I will. I kind of spoil my self more."

Although getting through involves several different processes described above, other aspects included making sense and leading a normal life.

Making sense. Making sense was the process women engaged in which enabled them to accept their situation and continue caregiving. Women struggled to make sense out of their situations that allowed them to come to terms with their fate and accept that there was little they could do to improve the difficulties they were faced with. They made sense out of their situations by accepting that there was nothing they could do about it. It was the strategy that most of the women used from the beginning through the middle and towards the end of their caregiving ordeal as a way to keep them going and helping them get through. They revisited the process of making sense over the course of caregiving when they were challenged by difficulties.

In this process, women sadly asked “why this happens to me?” or “why do I have to suffer caring for HIV infected husband?” It was a feeling full of sorrow and occurred early when she found out that her husband had HIV or that she, herself, had HIV. A woman explained her thoughts, “And I thought why? Why did he have to make me infected too? Why do I have to bear the brunt? I wasn’t aware. I am his wife. I didn’t do anything wrong. He was not home and I didn’t go out and be promiscuous. I am not the one who should get an infection I thought. Why he has to do this to me. Why I have to bear the brunt like this. Why our children have to be affected too.”

For HIV positive wives, it was very difficult to make sense of their own infection. All of them had only one sexual partner, their husband, and it did not make sense to them that they contracted HIV. They felt that HIV infection should not happen to them, but rather happen to bad or promiscuous women or prostitutes. A woman struggling to understand why she was infected by HIV stated, “Why do I have to have this. It shouldn’t happen. It shouldn’t happen, but it happened. Why? Because I was badly behaved? No, I am not. It is not my fault, then why do I have to have this?”

Gradually, women came up with the answer to their questions. These answers allowed them to have peace of mind and go on with life. Women’s answers were those of “it is my karma” or “I am unlucky”.

Some women believe that she had done bad deeds in the past life, and then have karma in this life. Therefore, in this life, they had to suffer in the forms of having HIV infected husband and giving care to him to pay back her karma. One HIV negative woman replied when asked why she took care of her husband. “Well….either he die or I die. I think I have karma. I think I have karma which I want to pay it all in this life.” When women faced difficulties in caregiving, again they tried to make sense out of the bad situation. "When he wakes up, he usually is in bad temper. He slams things, in other word, he is not considerate. I have to be patient… you know. At that moment, I told myself--this is karma".

Another woman tried to make sense out of her situation to be able to go on with her life. "I was thinking, why I have to come across this (picking the man who has HIV). I have many men who want to marry me. I think back and forth, it come down to—having karma. I have to pay it. I may did the bad things in my previous life, I must make merit in this life. I don't know how to think of it as short and easy to conclude as karma in order to be able to force my mind to accept it."

Another woman described how she made sense out of her own infection. "I think it is about unluckiness or karma because I don't know….I did nothing and why I have to have it. If I am a person who plays around, I can say that because I seek the disease to myself. But I think this is not the case. I didn't do anything. Why I have to bear karma. So I think may be it is because of my past karma or my own unluckiness."

Women felt unlucky when they compared themselves to other women who were happy and did not have HIV affected family. A woman felt that she is unlucky while her siblings are lucky to have a normal life. She noted "when I learned that I am infected, I was very angry, but there was nothing I can do about. I was angry…what?… why it happens to me?. Look at my siblings, they are living happily." Another HIV negative woman made sense out of her unluckiness, "Why it happens to me. There are a lot of people out there. My friends, they all have family and their families are happy and healthy. Why me?… having a sick husband and caring for him"; I look at other families…my friend's. Why they are alright, but I suffer." Making sense through believing their situation was related to karma or giving merit and knowing that there was nothing they could do about it, helped these women get through, or cope, with it.

Leading a normal life. Leading a normal life was another way that helped women get through hard times. Women tried to live as normal a life as possible. HIV had a clinical latency period that allowed the PLWA's to stay healthy for extended periods of time. In addition, anti-viral medications also helped symptomatic PLWAs regain their physical strength. The latency period varied and was unpredictable, but could last up to many years, enabling them to lead a normal life during that time period. The longer the PLWA's were in the latency period, the more they led a normal life. Wives wished that their husbands or themselves could stay healthy and lead a normal life as long as possible.

Husbands or wives who were in good health led normal lives as much as possible. However, there were some activities they needed to change. They had to hide their treatment, such as not letting others see the medications they were taking or letting others see them go to the clinic routinely, in order to keep the diagnosis secret as much as possible. The less people knew about the diagnosis, the more normal life could.

After a period of time, the PLWAs who were asymptomatic or had recovered from illnesses or whose health had improved, were more likely to return to their routine life and put AIDS on the back burner. A woman recounted that life turned back to almost normal after her husband's serious illness of fungal meningitis was resolved and they adjusted to his partially blindness. "Now life is okay…kind of normal… I tired not to worry too much. I try living normally like it never happened."

A HIV positive couple was able to lead normal life for ten years. Her husband's health declined over that period, but he was in fair good health still. The wife was asymptomatic and healthy. She said, "I almost don't believe I have AIDS, because I never had any symptoms."

Intervening Conditions

The social process of living with a sick and dying husband in which a wife made a sacrifice in providing care for their husband, varied according to the intervening conditions. These conditions included the wife's HIV status, number and age of children, illness factors, financial status, AIDS treatment, and the strength of one's support system.

Wife's HIV Status

HIV positive wives. Women's HIV positive status impacted women's caregiving and sacrificed experience in that they had to prepare for their own death and were coping with more problems than HIV negative women, e.g. worrying about children's future, worrying about who will provide care for themselves when they become ill, concerning about burdening their loved ones with caregiving.

Given they are going to die of AIDS, these women were trying to build financial security for family they will leave behind, find someone to raise their children, and prepare for their own caregiving in the future.

Women worried a great deal about their own caregiving in the future. Asking parents, siblings to care for the women was considered too much because that would burden or trouble them. It was perceived that HIV caregiving should be provided by the partner because it was a disease of shame, a sexual and self-seeking disease, not a natural disease "This disease is not like it just happens naturally; it is because he seeks for it. It is not like genetic diseases the come from parents." In addition, parents were not supposed to care for adult children; rather children were expected to care for their parents. Some women planned to go to the hospice monastery instead of troubling their own family once they needed someone to care for.

HIV negative wives. Wives who were HIV negative stated that this affected how they felt about taking risks related to contracting HIV while staying with and caring for their husbands. These women felt vulnerable to contracting HIV from their husband. Some women kept their fear to themselves rather than reveal it to their husbands because of the hurt it might cause. Yet, these women did note that it affected care-giving to some extent. As a women noted, "Honestly, I think every woman is afraid of this (HIV transmission). I also am afraid…you know…sometime…I don't know…sometimes, but I never tell him about this." A husband played an important role in her protection. He could help her stay safe from infection or he could force her to do unsafe things. One woman stated that her husband would force her to have unsafe sex with her when he wanted, so she had to threaten to leave him in order to protect herself.

Although it was unlucky that their husband had HIV, they perceived themselves as lucky that they were not infected by HIV. However, they still felt at risk of contracting HIV sexually and unintentionally from caregiving. Following the doctor's recommendation, HIV negative women protected themselves by using condoms, when it was a mutual agreement between herself and her husband. Some women believed condoms were effective, some did not. Some women preferred abstinence as the mode of protection.

Unknown HIV status wives. In this study, there were two participants whose HIV status was unknown. However, they assumed that they were HIV infected. The assumed HIV positive status impacted the two women's caregiving and sacrificed experience in that they had to prepare for their own death and were coping with similar problems as the women who were HIV positive were.

Number/Age of Children

Number of children. Women who did not have children devoted their time, money and attention to the caregiving of their husbands. Women who did not have children were more likely to take risk of getting HIV and dying together with her husband because she knew that there was no family member left behind to care for.

Having children made it harder for women to care for her sick husband and children at the same time. It was more stressful for couples who were both HIV positive to cope with the fact that they will leave their children behind, while it is less stressful for HIV negative women, because their children still had one parent left to raise them. HIV negative women with children had to prepare their career to support herself and her children after the husband's death.

For women who had children, the first thought that came to their mind once they learned about HIV affecting their family was their children. They thought about who would care for them after they die. Children will not be at their best and not receive good care because living with relatives was not as good as living with parents. As part of the preparation for their death, parents did everything they could to leave something behind for their children and work hard to save money, secure a place for them to live, or buy life insurance for educational funding.

Age of children. Women who had young or dependent children were concerned about their children being orphaned at a very young age or losing a father before they are grown up. Although children who are orphaned are likely to be cared for by relatives, women and their husbands still worried about their children's well-being. Parents of young children had to work hard while they were alive in order to build the best future for their children, such as saving money for education and living expenses. Women who had grown up children had less worry about their children's future.

Parents with young children had less difficulty in concealing the diagnosis from them. Whereas parents with grown children had a harder time deciding whether they should tell their children about the diagnosis. Some parents withheld the diagnosis until their children were able to understand or until they were older and had better knowledge about HIV from their school education.

Illness Factors

Stage of HIV. The stage of HIV in which women and their husband were in was identified based on the participants' account rather than through pre-defined clinical stages. Participants identified two stages of HIV as: healthy AIDS and sick AIDS.

According to participant's perceptions, healthy AIDS referred to the stage that the PLWAs do not develop symptoms or have minor symptoms such as skin disease, oral thrush, diarrhea, or low fever. Sick AIDS referred to the stage that the PLWAs have major symptoms such as TB, meningitis, and pneumonia, etc.

Husband's health condition. Stage of HIV determined health's condition of the PLWAs. The study participants reported two types of health conditions: healthy and sick. Healthy condition meant that the person could perform daily routines or did not require health care from physicians. Sick condition meant that the person could not perform his daily routine because of the illnesses or the person needed medical attention from physicians.

Stage of HIV and health condition similarly affected various aspects of the sacrifice and caregiving experience. Husband's health condition determined the caregiving activities and the degree of exhaustion women had. It was common that husbands' health fluctuated, and when their husbands were not sick, women perceived it as calm-down time. Because husband's health condition determined women's caregiving and daily activities, calm-down time referred to the time that husbands were not severely sick and did not require intense caregiving at home or in the hospital. It was the time that husbands were stable, feeling well, able to eat, sleep, and function normally. During this time, women's daily life activities were not affected. On the other hand, if husbands were very sick by severe opportunistic infections, women's lives were interrupted and they often had to miss work or spend the night in the hospital.

Over the course of HIV illness, most husbands were sick with multiple illnesses and went back and forth between sickness and health. Their degree of sickness and health affected many aspects of the lives of both the husband and wife. Table 4 summarizes these aspects. Not all of these occurred with every couple in the study, but were typical for many.

Hospitalization made it difficult for most women. They experienced exhaustion and fear of their husband's death, worry about medical costs, and worry about children at home. A woman noted, "It was very hard when he was in the hospital. I went back and forth and did everything alone. I was very tired and stressed. I couldn't sleep and had bad headaches. I ran here and there by myself, worrying about my son at home and worrying about my husband at the hospital."

Table 4

Husband's Condition and Effects on Family Life

Sick	Healthy
•Husband was dependent	•Husband was independent, functional, can work
•Increased demand for caregiving ,	•decreased demand for caregiving
•Cannot work--loss of income	•Can work---regain income
•Wife's exhaustion	•Wife's less exhaustion
•Wife miss work, quit job	•Wife resume work
•Daily routine is interrupted	•Life gets back to daily routine
•Increased caregiving demands	•Decreased caregiving demands
•Wife's fear of husband's death	•Wife's fear of husband's getting sick
•Loss of hope, the end is near	•Regain hope, it is not the end yet
•Increased medical expenses	•Decreased medical expenses

When the husbands were hospitalized, it was more burdensome for women who had to work at the same time. A woman whose husband was blind from an opportunistic infection explained, "When he was in the hospital, I was more burdened. I have to go to work and come back here and take care of him. I don't really have time to get rested. But if he's fine and he is home, I don't have so much hard time"

Financial Status

AIDS treatments are expensive and nature of HIV disease involves multiple infections which may require hospital care. Their financial background determined their caregiving experiences. Women who had a strong financial background had more choices in their living and caregiving.

One couple was able to afford to move out from his parent's house to have more privacy in living with HIV. Some women could afford to stay at home to give care and did not have to worry about their children' future. Some had to work hard to save money for the future treatments because of their poorer financial background.

Wealthy couples could afford the anti-viral medications whereas other couples who did not have a strong financial background had less chance to receive anti-viral drugs because most of them had to pay for the medications out of their pocket. Thus, their health was more likely to deteriorate faster than those who could afford the drugs. In addition, some women had to assume multiple responsibilities of working and caregiving because they had to support their family financially. These women were more likely to have more difficulties living with and caring for their husband.

AIDS Treatment

The majority of the husbands and wives who were HIV positive did not receive anti-viral medications. Those who received anti-viral medications were healthier and had higher hopes for living longer. Taking anti-viral medications directly affected husband's condition in terms of frequency of illness episodes and number of opportunistic infections. Women of healthy husbands had less fear of death and could lead a more normal life. Healthier husbands did not demand a great deal care from their wife compared to those who frequently became sick with opportunistic infections. However, women whose husbands were taking anti-viral drugs encountered a different stressor in relation to monitoring and insisting their husbands to take the medication.

Strength of One's Support System

When dealing with difficulties, most women did not receive the social support they needed because they did not reveal the HIV diagnosis due to fear of being shunned. This concealment diminished their chances of receiving needed support. Women who lacked support were often left feeling alone and isolated. A woman who never received support from anyone, even from her husband and daughters, was having a hard time dealing with the burden. She admitted, "Sometimes I want encouragement. I want somebody to comfort me, I only want nice words."

Although some women in this study did not receive support, there were some who did. Some people, such as extended family, friends, and neighbors, did support them despite knowing about the HIV diagnosis because they felt sorry for them. Some people gave support without knowing that they had HIV. The tangible support (e.g. money, caregiving assistance), and emotional support (e.g. encouragement, praise, visit, consultant) they received helped them get through the difficult times better than those who did not. A woman said, "My neighbor, she is very nice. She admires me and encourages me greatly. I seem to have strength to fight more. I can get up and do more. When I don't get encouraged, I feel down and think that why I do this, because it is exhausting."

One woman described the different kinds of support from friends she had while caring for her blind husband. "One of his friends at work knows about it (AIDS). He helps us, when we were struggling, he will pay a visit. When my husband is sick, he will visit us and encourage us, tell us not to give up. He knows everything. He does not shun us at all. He told my husband what ever happen, we are still friend. There is no way he will shun him because this kind of disease is not going to infect others very easy. He said he will keep this as a secret and he will never tell anybody. When my husband was sick and was in the hospital, the people asked him what he has. He said that my husband has other disease. He always helps. Like last time, I talked to the nurse like you and I got out crying. So I talked to him and he comforted me." She added, "Nowadays if friend doesn't help us, we would have hard time."

A woman was very sad about losing the opportunity to have a baby. She felt better when she received social support from her family, "I felt good when there were many people encouraging me, my mother, and my siblings…people around me. When I am sad about wanting to have a baby, they comfort me. They said it is okay if I don't have a baby. I talk to my mother on the phone, my mother always encourage me. I am glad that our relatives do not shun us or leave us alone. They are worried about us. I felt a whole lot better."

For these participants, however, the most important support was from the husbands they cared for. A woman who was trying to get though her sadness about being infected by HIV, described the emotional support from her husband. "Nowadays we consult each other. He gives me encouragement. He pleases me. Whatever I want he gives me. He takes me with him everywhere. So, I feel less stress."

In summary, the process of sacrificed caregiving were influenced by a set of conditions concerning wife's HIV status, number/age of children, stage of HIV and husband's health condition, financial status, AIDS treatment, and the strength of one's support system. These intervening conditions directly or indirectly alter women's experience and actions of care-giving.

Consequences: Outcomes of Sacrificing

Consequences were outcomes of the action/interactions taken in response to the central phenomenon. There were self, family, and social consequences of the sacrifice these women endured. Sub categories under the category of self were emotional rewards, suspended life, negative effects on health, job/work/business, and exhaustion. Subcategories of family were husband's longer survival and family staying together. The last category, social consequences consisted of subcategories of isolation, discrimination, being labeled as HIV positive women/AIDS widows.

Self

Emotional rewards. Providing care for husbands emotionally rewarded women in different ways. It gave women the sense of happiness, pride, appreciation, mental strength, and merit.

Women were happy when they saw their husband feel happy and comfortable because of their care. A woman felt good that her care met her husband's needs. She noted, "I'm just happy. (laugh). I can't describe…I'm happy because I feel good in my heart. Whatever he wants I can give it to him." Another woman was happy to see her husband alive, "I am happy that I wake up every morning and I see him. Although he is like this, but I am still happy he is here, he does not leave me." Knowing that she had done good things for their husband gave women a sense of pride. A woman described the feelings she had as she cared for her husband the best she could, "I feel proud. When I do for him, my heart…oh…it is hard to explain. It is like…happiness. I am happy just to do things for him."

Some women were proud of being the only person their husbands trusted and cared about. One husband trusted his wife, so he gave her authority in making decisions about his care and funeral. His wife said, "I'm happy. (smile). I am very happy. He told me that if he dies, don't tell his parents. He asks me to take care of it myself." Many women received praise from their friends, neighbors and even strangers who saw them provide care to their husband. Most women vowed that they will do their best in taking care of their husband. Although, they did not expect praise about being a good wife from others, they appreciated it when they received it as it conveyed to them a sense of fulfillment. Women felt appreciated when their husbands complimented them about their dedicated and hard work. A woman noted, "He said that I am the best. He said I take care of him the best. I love him more than his own mother. He said like this. Taking care him and love him more than his own mother."

Getting merit was another reward women perceived when they provided care for their husbands. A woman explained, "I do this for him. I get merit too. Sometimes I thought, I do good thing for someone who can not see, that is a merit. I feel happy. It is like… I don't have to worry so much." Some women felt that they gained emotional strength and discovered their potential after the difficulties they had been through. "When it's the time, everybody can do it. Before, I thought I had a timid heart; I can't drive, I am afraid to drive. Only hearing others honk a car horn frightens me. Nowadays, it is not like that. It is different like a forehand and a backhand. I am more calm." Some women gain a sense of accomplishment due to their sacrifice to stay with him and care for him. A woman said, "I never regret staying with him. At least, I am the one who is behind his being here today, and nothing had happened."

Suspended life. The category of suspended life was derived from the accounts of HIV negative women. Suspended life referred to women's temporary status of waiting for life, for personal needs and desires until the caregiving ordeal was over. Because HIV negative women will live after their husband's death, they perceived their caregiving role as doing what they needed to do the best they could until it is over and they got back to their life without HIV. The nightmare of living with HIV and the responsibilities she had were temporary and would end with their husband's death. They had their life without HIV and for now, they needed to set that aside and do what was most important, which was caregiving for a sick and dying husband.

A woman suspended her ambition to pursue education and career advancement to devote herself to care for her husband. She explained, "My husband felt bad that he burden me. It is like he pulls me down with him. I should advance my career better than this. I have a future await me. Before he got sick, I thought about going back to school for a master degree. He felt that if I don't have him, I will have better future. But I said—it is okay. Only if I am happy and can do it well, I will go back to school. But I chose (to care for) him, I will do my best with my marriage."

Another woman suspended her role of grown up child taking care of her elderly parents in order to devote time and energy to her husband's care. She was waiting to be released from her current responsibility to fulfill her role of caregiver for her elderly parents. "After this has passed, I will be with my family. I want to be with my mother. Now it is like I love my husband more than my parent."

A women's parenting responsibility was also partially suspended until the caregiving of her husband was over. A woman suspended her lifestyle, pleasure activities because she had to devote herself to caregiving and working to support him. A woman said "After his death, my life will go back to normal. My life will be more comfortable. I don't have to get tired since I wake up in the morning. Before he has this, I got up late on the weekend and read books all day."

Negative effects on health. The pressure of taking multiple responsibilities and the overload of caregiving tasks, led to negative effects on women's health. Psychologically, women suffered from stress and depression. A woman said, "I was so stressed when it gets hard…like….when I don't have money and husband is very sick. It is too stressful. I was so depressed that it sickens my stomach and I threw up. I was very worry and sad."

In addition to effects on psychological health, women's physical health was affected. Some women suffered from headache, fatigue, losing weight, lost of appetite. A woman described, "I think I lose some weight. Before this, I weigh more than this. I feel that I got skinnier….My husband told me to eat something and eat a lot of them. And I told him I couldn't eat. I was so tired. Because when I'm tired, I can't eat at all."

Given the vulnerability of being infected themselves, HIV positive women risk contracting infectious diseases such as TB and herpes from their husband. An HIV positive woman, whose husband was hospitalized twice in the last six months, contracted TB from her husband. "I'm also sick from TB, but I'm never hospitalized. My husband is sicker than me. It was worse when he was hospitalized because I was so tired caring for him and came home having fever at night."

Job/work/business. Women took the risk of loosing their job when they stayed with and cared for their husbands. Women who were employees were at risk of discrimination in the workplace just because they were wives of persons with AIDS, let alone being infected by HIV themselves. A HIV negative woman just resumed her work after taking a leave to care for her husband. Her secret about her husband's diagnosis got out to her boss. She recounted, "Human resource staff called me and ordered me to get a test and bring the result to him. I think they thought that I am HIV positive, and they don't want to accept me back because they have to pay for my medical bills. And if they don't accept me back, they have to pay me when they fire me. An employee who is HIV positive was fired before. They thought if my test shows I am positive, I will not dare bring it back to them." Some women worried about the exposure when the husband is terminally sick because it is hard to conceal that they had HIV. They perceived that their job would be jeopardized again.

Some women had a limited choice of occupation if others knew about their HIV diagnosis, either of their husband or their own. They could not work in sales, because customer will be afraid of contagion and not buy the merchandise. A woman was going to move back home to stay with her grandmother because of the financial problem. Everyone in her village knew about HIV diagnosis. She explained, "I discussed with my husband about what will we do for a living when we are back home. What are we able to do? Working in the farm or orchard….we can't do it because we can't endure the sunlight. I thought about raising chickens, but nobody will buy chickens from us. They are afraid. I can't open a store, because I don't have enough money, besides villagers don't want to go to my store." Foreseeing similar circumstance, a woman carefully selected her future occupation as a dressmaker because it enabled her to work alone at home without seeing a lot of people when her HIV appearances occurred.

Exhaustion. Given the nature of HIV disease, unrelenting and demanding caregiving of PLWAs was exhausting and burdensome. Women feel burdened when they cared for their sick and dying husbands. Their multiple responsibilities of caring for a husband and family at the same time, led to both physical and emotional exhaustion.

A woman described her exhaustion from caring for her husband and working to support her family, "I have to do it for him….bathing, shampooing, grooming, everything…I did everything. I am very tired. I don't know; I don't know how to find thing that can measure it. Many times, I had to be hurry into finishing caring for him, so that I could get out of the house and bought merchandise for sale. I go out to work in the afternoon. Normally, I wake up at 4 or 5 AM. I went to bed at 1 AM. I feel sleepy often while I am driving home in the evening. Feel sleepy on the way to work too." This woman not only experiences physical exhaustion, but also emotional exhaustion from dealing with her daughters and husband's family demands, she said "I feel awfully tired. I don't know anything that can measure my tiredness. Thermometer can measure temperature, but can't measure my tiredness at all. I am both physically and emotionally tired."

Emotional exhaustion not only came from dealing with family and caregiving problems, but also came from dealing with the burden of the health care system such as it taking a long line to get care, the high cost of medical care, the complexity of health care system, and dealing with power of health care providers.

Family

Husband's longer survival. Women perceived that the better the caregiving husbands received, the better their quality of life, and the longer they will live. For some, good caregiving had saved their husband's life. A woman gave an example of the couple she knew. She thought that because the wife did not provide good care for her husband, her husband lost courage to live and quickly died. She explained her thoughts about her own caregiving, "I think what I had done for my husband extended his life. My husband also said that he was saved to live a while longer." Another woman said, "My husband, he doesn't want anybody else when he is sick. He only wants me…only me doing everything. It is that I am his everything. He told me he survives because of me."

In addition to physical care women gave to their husband, providing psychological support increased their husbands' chance of survival. Women believed that husbands' courage and mental strengths led to increased physical strength and helped to prevent their health from declining too rapidly.

A woman tried to make her husband free of worries and stress, so that his mental strength promoted his physical strength. "…I want him to be happy. I want him to feel no trouble, no stress. If he is stressed, his body is still fine and he will not get very sick."

Family staying together. This category was derived from women who had children. Because of women's sacrifice by staying with and caring for their husband, the family did not fall apart. Their children had both father and mother to stay with.

When things became more difficult, some women were thinking about giving up their fight with HIV. A woman was thinking about leaving her husband when he was difficult to live with, but she quickly changed her mind because she wanted her son to live in a family completed with a father and a mother. She recounted, “I sympathized with my son. If I leave, how will he live without me? I once asked my son if I live somewhere else, what he will do. He said he will come live with me wherever I live.” Another woman was motivated to stay with her husband and fight with HIV in order to keep her family together as long as possible. She said, “I told him (husband) that we need to fight. We can’t give up. If we give up, then what’s about our children? I said something like this. If something happen to us, our children are so young.”

Social

Isolation. Because of the strong social stigma of HIV/AIDS, women were more likely to keep the diagnosis secret and present their public self while keeping private feelings and thoughts inside. Doing so eliminated their social connections with family and others.

The public/private self and the concealment of the diagnosis isolated HIV negative women from the extended family who did not know that her husband was battling with HIV. One woman was even more isolated because she had to conceal the real reason she did not have a baby of her own from her extended family, who did not know that she had to use condom to protect herself from contracting HIV.

An HIV negative woman who lived with her husband in Bangkok canceled their occasional trip to visit extended family in a rural town once her husband developed HIV related symptoms because they feared discrimination. She was lonely and despaired because she could not see them. She had no children and he was a quiet man who was not a good supporter. “We must live like this, only the two of us, because none of us tell our family about AIDS. If we get sick, I wonder if my family will take care of me. Whatever going to happen, I will only think we have only the two of us.” Another HIV negative woman described her loneliness when she wanted to share her suffering with someone else. She said, "It is aloneness, I am so alone…don't know whom I can discuss with. Don't know whom I can talk to. When I feel tired, in my mind…I want to tell someone."

A woman whose husband was diagnosed with HIV for seven months described her living in isolation. This woman associates her life as living in darkness as she explained, "In the past seven months, it is like I was living in hell. It is like I am in total darkness. I don't know what to do. I don't know whom I discuss with. I think by myself, do things and solve problems by myself. I want to what I should do, but I couldn't ask anybody". Women's isolation was very immense and women respond to it by crying alone. A woman recounted, "It was like….my heart was full of trouble. (I) wanted to tell somebody, but didn't know whom I could tell. I was scared that they will feel disgusted at us. I just laid there and kept crying".

Not only women who were suffering could not share, neither could women about their happiness. A woman who had just found out that she is HIV negative after assuming that she was infected for seven years, wanted to share her happiness with anyone else, but she could not. She said, "The first day I learned that I am not infected, I was happy…oh…I was very happy. But I can't express my happiness much because I am afraid that I will hurt him by the fact that I am not infected."

Discrimination. As a result of unreasonable fear of contagion in most of the people in Thai society, women and their husband and family members suffered from social discrimination and rejection. They were discriminated against by their own family, relatives, friends, coworkers, neighbors and even strangers. A woman experienced discrimination from her husband's family and recounted, "…his mother knew about this (HIV infection), but they didn't come to visit him. They were quiet. They didn't come see us…no contact at all. I don't know…seems like they feel disgusted at us. I didn't show any feeling. I talk to them like I used to, but they do not act normal with us. My husband might have felt it. He keeps distance with his relatives. Once in a while, he goes see them for a bit." Another husband was left at the hospital after his relatives who took him there learned that he had HIV.

Discrimination and shunning was more prevalent in small communities where people know each other than in urban centers. One woman had to move out from her mother's house to avoid feeling rejected from people in the neighborhood. Another woman disclosed her diagnosis to her mother for emotional support and her mother then told her relatives and the news spread out to other villagers. She said, "They (relatives) tell others that I have this and that. So, other people don't want to get close to me." Another woman shared her story about discrimination her son experienced. She said, "My husband was going to have a hair cut, our neighbor said to my son—why do you let your father come here (the barber shop). If he comes, other customers will not come. They told my son like this. My son doesn't understand what he said, so he told me. I thought he went over board to say something like that to my son." Another woman said, "In my village, people will gossip that the person in this house died of this and that. I was so afraid how the persons who were left behind will live. I am afraid how my son will be if people say that his parents die of this disease."

One women and her husband experienced rejection and shunning from strangers. She said, "Yes, I have. I saw some people looked at us. He was very skinny at that time, but still can walk. We were walking on the street, then people stared at us like….from head to toe, like…turning their head back to keep looking at us. We felt bad that people behaved like this." Because of the look people on the street gave to PLWAs, some husbands who had AIDS appearance avoided going out of the house.

Given the strong social stigma against PLWAs in Thai society, several women and their husbands were living with fear of being shunned by others. An HIV positive woman noted, "I am afraid that people will shun us. There are people who say that if they know who has this, they will not get close to them. They will not get involved with us because they are afraid of getting infected. So, we decided not to tell anyone. So it is only between the two of us. We didn't tell others in the family."

An HIV negative woman anticipated discrimination from her husband's family. She explained, "If one day, people know….for example, if my husband dies, his family and relatives must know. I don't know when that day comes, what will I do? Will they shun me? Think about it…I had been living with a person with AIDS for years; everybody must think that I have AIDS too. I think…think…think a lot."

Being labeled as HIV positive women. This category was derived from the accounts of HIV negative women. Thai people assumed that sexual partners of PLWAs will certainly contract HIV from the infected person. Therefore, society labels them as being HIV positive also. Since PLWAs usually conceal their HIV status, people are more likely to think that wives of PLWAs lied to them about being HIV negative. A woman in this study was fighting a rumor at work that she had AIDS because her husband's diagnosis was disclosed. She was trying to correct the accusation, but most co-workers did not believe her despite her countless refusals. She finally showed her test result to one of the coworkers in order to spread the truth out. Still, the labeling remained and she gave up correcting the information.

Some HIV negative women never refused the accusation that she was living with HIV. She internalized that she would accept that false label until time disproved others' accusation. Overtime, her being alive will be proof enough that she was not infected by HIV. It was common that people learned about a husband's HIV diagnosis after his death. Women were more likely to be exposed too. Once the public learns that they were AIDS widows, they will assume that they were also infected with HIV.

An HIV negative woman said, "My husband was worried that after his death, society will look at me badly and shun me. I said to him I already prepared myself for that social label, and that one day I have to get such response from people. But I think I can accept that. That is okay, I am prepared. When people said things and I overheard---her husband has it (HIV)… something like that. Well! They are regular folks……….I know what I am doing, aren't I? For others, time will prove it, it just takes time. Those, who can wait, will see. When they are tired of saying that, they will stop by themselves. "

Public did not know that there were many wives who did not contract HIV from their husbands. When the women told the truth, nobody believed them. This affected a women's credibility. An HIV negative woman, who just got back to work again after taking a leave of absence, said "…since I work there, everybody acts normal to me. I told them I am HIV negative, but I don't think they believe me."

Summary

This chapter presents the findings from interviews with 20 Thai women caring for their husbands living with HIV/AIDS. Through grounded theory analysis of interview data, six major processes emerged from the data: husband living with HIV/AIDS, Thai culture, sacrifice: living with a sick and dying husband, sacrificed caregiving, conditions influencing sacrificed caregiving, and outcomes of sacrificing.

Thai cultural beliefs regarding the religious belief, meaning of marriage; the meaning of HIV, source of infection and caregiving, the role of women in society and as caregiver, influence the phenomenon of women caring for their husbands living with HIV/AIDS. Husband living with HIV/AIDS was identified as the antecedent condition that lead to the social process of sacrifice which was central to the experience of women caring for their husbands living with HIV/AIDS. Sacrifice was viewed a process of living with a sick and dying husband in which wives made a series of sacrifice in choosing to staying to care for their husbands, giving up what they had or should have had if it were not for their husband's illness and learning to enduring struggle associated with providing care. By providing care for a sick and dying husband, women utilized five strategies of sacrificed caregiving: giving care, preparing for death, taking multiple responsibilities, taking risk of HIV infection, and getting through. Six conditions identified by participants directly and indirectly influenced the strategies of sacrificed caregiving. They include: wife's HIV status, number/age of children, illness factors, financial status, AIDS treatment, and strength of one's support system. The outcomes of sacrificed caregiving were organized in terms of self, family, and social domains.

CHAPTER FIVE

DISCUSSION

The aim of this grounded theory was to develop a theoretical explanation of the social processes involved in the caregiving experience of Thai women caring for their husbands living with HIV/AIDS in Thailand. Data from qualitative interviews with 20 Thai women, who were the primary caregivers of their husbands, were analyzed using the grounded theory method. The study findings suggest that the caregiving these Thai women performed for their husbands involved much sacrifice in multiple areas of their lives and that integral to this sacrifice were the embedded meanings of Thai culture and Buddhist beliefs. This chapter discusses the research findings, the implications for future research, nursing practice and public policy, ethical considerations and study limitations.

Discussion of the Study Findings

The purpose of the discussion is to identify similarities and differences between the findings in this study and the extant literature and to illustrate how the present study contributes to the body of knowledge of HIV/AIDS caregiving in Thailand. In addition, the discussion of the meaning of caregiving and factors that contribute to caregiving sacrifice are also presented.

This grounded theory study identified the social processes that explain the phenomena of caregiving from the wives perspective. In the processes involved in sacrifice, women expended themselves for the benefit of their husbands. They placed their husband's need for care before their own well-being. Influenced by the context of Thai culture, wife caregivers who were living with a sick and dying husband sacrificed their own well-being by choosing to stay with their husbands to provide care, by giving up external and internal resources, and by enduring the struggle brought upon them by HIV illness. Sacrificed caregiving were the actions taken by wives when they performed activities associated with giving care, such as, preparing for their own, and their husband's death, taking on multiple responsibilities, taking risks of HIV transmission, and coping with the day-to-day struggle of their caregiving ordeal.

The sacrifices women made were to stay in the relationship to provide care for as long as it was necessary, putting their own lives on hold and giving up most of their dreams, way of life, and future opportunities. They forgave their husbands for their unfaithful acts and for passing HIV on to them. How HIV/AIDS affects marital relationships has not been thoroughly examined. However, the research that has been conducted confirms findings found in this current study. Research by Chaiparsit (1994), Jongsathitman (1995), Phengjard (2001) and Songwathana (2001) reported that women tended to forgive their husbands and chose to accept their situation, even when the news of HIV infection revealed their partner's extra marital sexual activities. Empirical evidence from research on HIV pregnant women indicates that women are more likely to stay in the relationship or marriage after the diagnosis if they had a positive relationship with their male partners prior to the diagnosis, regardless of who and what was the source of infection (Chaiprasit, 1994; Manopaiboon, et al., 1997). The findings of this study concur with those conclusions that the husband's good behavior in the past was the primary rationale women chose to stay in the relationship. Women forgave their husband's behaviors because they believed their husbands should not be punished for their infidelities, especially when the actions were not intended was not intended to cause harm, and/or because they considered his past goodness was more important than his current mistakes. However, there were also other rationales women reported in this study of why they chose to stay in the relationship. These rationales included: sympathy, because he was dying of HIV/AIDS; understanding, because their husbands did not intend to pass HIV on to them; acceptance of what had happened, because they could not change the past; and coming to the realization that condemning their husbands would not solve anything. These rationales have also been documented in the literature (Songwathana, 2001; Treemulka, 1996; Wathanapailin, 1996)

Women sacrificed their well-being by accepting the condition of living with a sick and dying husband and providing the caregiving responsibilities and hardships that accompanied it. Similar incidents of women's acceptance of these types of situations were documented in Songwathana's study (2001). She found that wives took on the role of caregiver for their husbands even though their husbands transmitted HIV to them. They accepted their condition with patience and continued to provide care for their ill spouse.

Women in this study provided care for their husband for various reasons. The rational for staying to care has not been thoroughly explored in other studies. However, Songwathana's work supports some of rationales women reported in this study. One of them was that women provided care because they perceived it as a wife's duty. Influenced by Thai socio-cultural values, women perceived that it is wife's role and responsibility to provide care for a sick husband. Accepting care for husbands because of a sense of sympathy and love was reported by women in this study, and was parallel to the Buddhist's concept of "metta" or loving kindness women in Songwathana's study reported as the reason they provided care for their husbands. Another study of HIV/AIDS caregivers confirmed that caregivers provided care because of the sense of love and obligation they have for their family members (Phengjard, 2001). Other reasons included the need to fulfill their moral obligation and free themselves from social blame of being a bad wife. A concern for children as the reason of caregiving has also been reported in previous studies (Songwathana, 2001; Wathanapailin, 1996). This may be explained by the meaning of marital and familial relationships in the context of Thai culture where life and identity of woman are strongly tied to marriage and family (Limanonda, 2001). The rationales of caregiving that have *not* been documented in the literature, and are reported in this study, included a sense of loyalty and attachment wives had for their husbands. It was observed that most women did not have just one reason to stay and provide care, but had multiple and combined reasons to provide care for their husbands. This observation reflects the complexity involved in caregiving decision making.

In this study, women's acceptance of caregiving is organized according to type of acceptance and placed along the continuum from willingness to care to duty to care. Women who were willing to care were totally devoted to their husbands and were able to cope with their hardships and maintain a positive attitude toward caregiving. On the other hand, women who provided care because caregiving is a wife's duty, felt that they *had* to provide care and often resented their husband because of it. They did not devote themselves to caregiving willingly, and often questioned their decision to care. They were more likely to struggle with their caregiving and had more difficulties getting through the hard times. The patterns of willingness to care and duty to care described by women in this study correspond with the concept of family acceptance of care reported in a research study conducted by Bhutchon and colleagues (2000). They categorized family caregivers according to their acceptance to care: conditional acceptance and unconditional acceptance of family. The group of wives in this current study, who were willing to care, is comparable to the family with unconditional acceptance in Bhutchon's study (2000). In these families, the caregiver provides care with eagerness and devotion in order to promote well-being to the receiver of care. Families, who accept caregiving with conditions, perform caregiving in a less caring manner and care is provided when it is needed, or asked for and provided based on caregiver's convenience and availability. The group of wives in this current study who perceived caregiving as their duty is comparable to this group of caregivers with conditional acceptance.

The women in this study sacrificed a large part of their life in order to care for their husbands and gave up many of their future goals, opportunities, life expectations and resources in order to do so. Women used their financial savings to save their husband's lives. Families devoting all their resources into the PLWAs health care has also been reported in the work of Bhutchon and colleagues (2000) and Muecke (2001). Giving up personal time and time with children was reported by women in this study. The effect of caregiving on caregiver's social life, including their personal time, had not been reported previously by Thai researchers. However, the studies of Thai families who cared for PLWAs (Janjarat, 1994; Songwathana, 2001) provide evidence of the effect of caregiving on time for children when wives became the caregiver, especially when the care receiver falls ill or was in the terminal stage of HIV.

Giving up reproductive opportunities because of their husbands HIV has been previously documented in the literature (Sivaraman, 1999). However, the findings of this study offer further information regarding HIV negative wife's reproductive issues. HIV negative wives gave up their desire to have a child because they had to use condoms to protect themselves from HIV. These women felt sad and incomplete when they were not able to get pregnant and be a mother.

Women also sacrificed their dreams and goals when AIDS affected their lives and they became a caregiver. Dreams and goals related to family and children are normally expected by married women in Thailand. Some HIV positive wives sacrificed their chance to receive health care when there were limited financial resources because they felt that their health needs were less of a priority than their husband's HIV care because they are less sick. Also, some women gave up their life-style or their way of life when they decided to stay with and care for their husband. Although wives' experience of giving up their dreams, goals, and life-styles, has not been described in Thai literature, western research on HIV/AIDS caregiving identifies the caregiver's multiple losses related to several aspects of caregiver's personal and social life, such as loss of their former way of life, loss of an anticipated future, and loss of personal freedom and time for themselves (Brown & Powell-Cope, 1993; Reynoldd & Alonzo, 1998). However, the particular experience of giving up or losing opportunities to receive health care, has not been documented in the literature. Knowing the sacrifices women make that may potentially affect their health and well-being has the potential of contributing to better care practices for women's health in Thailand in the future.

Some women in this study gave up their own lives to die of AIDS with their husband. As part of caregiving, some HIV negative women gave up their chance to survive by not protecting themselves from sexual transmission in order to protect their husbands from feeling rejected or alienated by them. Fear of abandonment is common among Thai people affected by HIV (Songwathana & Manderson, 2001). Women in this study perceived that using condoms would hurt their husband's feelings. Thus, they elected not to use condoms to protect themselves so that their husband's feeling would not be hurt. The perception of condoms as a form of discrimination has been documented in a research study of twenty-four

Thai couples whose female spouses were HIV positive but their husbands were not infected (Kongsuriyanavin, 1997). Kongsuriyanavin found that some HIV negative husbands did not use condoms to protect themselves from contracting HIV from their wives because *they* were worried about hurting their wives' feelings. Further research should explore condom use among couples with HIV in order to provide better understanding about their perceptions and to promote HIV prevention behavior. Similar perceptions of other types of HIV protection being a form of rejection has also been reported in the literature. Caregivers in some studies perceived that wearing gloves would make the care receiver feel rejected (Janjarat, 1997; Phengjard, 2001). It is important that HIV prevention measures, such as condom use and gloves, and their meaning as being symbols of discrimination and rejection, should be further explored.

Empirical evidence indicates that some Thai couples who are both HIV positive do not use condom after the HIV diagnosis (Prompukdee, 1994; Siriroj, 1994). There is also literature that reports that some HIV infected husbands do not use condom with their wives because they did not reveal their HIV status to them; and there were some HIV infected husbands who refused to use condoms with their HIV negative wives because they thought they would have less sexual pleasure (Limanonda, 2001). Thai literature suggests that generally Thai wives have no power to negotiate condom use to protect themselves from HIV because of their subordinated position (Boonmongkol, 1998). However, HIV negative wives' behavior of choosing not to use condoms in this study was reported as an act of choice and a result of mutual agreement between a husband and wife not to prevent the transmission. In this study women risked themselves to HIV infection as a part of caregiving for their husband. This finding expands the definition of HIV/AIDS caregiving in the literature. For wife caregivers in this study, in addition to physical and emotional care, meeting their husband's sexual needs and sometimes taking the risk of contracting HIV infection so the husband would not feel rejected, were considered an aspect of the caregiving.

The findings in this study further revealed that three HIV negative wives gave up their opportunity to live, because they had a strong sense of love and attachment to their husbands and wanted to die of HIV/AIDS with their husbands. Thus, they were not afraid that they would be infected by HIV because of unsafe sexual contact. HIV negative wives' perception of dying together with their husbands has not been previously reported in Thai literature. It is interesting to note that in many of these cases women seemed to have an idealized perception of what dying together meant, when in actuality they would most likely outlive their husband and die alone without anyone caring for them. This issue of HIV negative wives perception of dying together merits further investigation.

Wife caregivers in this study endured many struggles while living with a sick and dying husband. They endured the fear of sickness and death. Congruent with the study of Brown & Powell-cope (1993) concerning loss and dying in caring for a family member with AIDS, the most painful experience for HIV/AIDS caregivers was facing the possible death of their loved one. Not only did women worry about their husband's illness and death, for some women, they also feared their own sickness and death when they witnessed their husband's failing health. This finding supports the experience of wife's caregivers described in Songwathana's study where wife caregivers who were sick themselves constantly worried about their own death, the death of their sicker husband, and their child. Fear of sickness and death of women who are HIV infected themselves is also reported in literature of PLWAs (Chaiparsit, 1994; Tansrirathnawong, 1998; Wattanaphilin, 1996).

Women in this study lived a private and public life that involved hiding private thoughts and presenting another self to the public in order to prevent their husband's or others' anxieties or worries, to create a sense of strength and security for their husbands, and protect themselves and their husbands from discrimination. The utilization of public and private self to prevent discrimination was parallel to one of the several strategies of *keeping silent* described in Phengjard's study. Caregivers utilized strategies to keep silent to protect the PLWA and family members from the negative reactions of others. Two of the strategies of keeping silent in that study were "feigning happiness" and "giving no clues". Presenting public self to prevent others from anxiety or worry and create a sense of strength and security for others has not been documented in Thai literature.

Women in this study anticipated and experienced discrimination from their extended family and communities. This is because Thai society has negative perceptions about AIDS and holds great fear of contagion and feelings of disdain and disgust towards PLWAs and their families (Plai-noi, et al., 1996; Songwathna & Manderson, 2001). It is common that people associate with a stigmatized person, become stigmatized themselves (Goffman, 1963). Confirming Goffman's concept (1963) of courtesy stigma, wife caregivers and family members of PLWAs in this study also experienced the stigma attached to PLWAs. Although nine women in this study were not infected by HIV, as a wife caregiver of a PLWA they also suffered rejection and discrimination from relatives and other people. Similar phenomenon, called "guilt by association", was described when caregivers were stigmatized because they associated with someone with AIDS (Powell-Cope & Brown, 1992).

Stigmatized persons manage their stigma in many ways, including concealment, disclosure, passing and covering (Goffman, 1963). The findings in this current study demonstrated that women were forced to live in secrecy with fear of discrimination and rejection. They were more likely to keep their HIV status a secret. Women in this study hid their caregiving and were careful to protect the information that their husbands had HIV. They lied about the diagnosis, withheld information, or made excuses in order to keep the HIV secret for as long as possible. Similar strategies were reported as a part of living with the secret of HIV/AIDS family caregivers (Baker, Sudit, & Litwak, 1998; Powell-Cope & Brown, 1992).

The intentions behind these actions included fear of discrimination and rejection, fear that the diagnosis would worry their loved ones, fear that the diagnosis would threaten their employment. Similar intentions were described in several other studies (Phengjard, 2001; Powell-Cope & Brown, 1992; Sangchart, 1997; Songwathana & Manderson, 2001). The theory of living in secrecy was developed from Thai mothers living with HIV infection (Thampanichawat, 1999). Thampanichawat described that mothers were more likely to disclose their HIV status if they expected benefits for themselves or for significant others, but were more likely to conceal it if they perceived threats o themselves or to significant others. Powell-Cope and Brown (1992) found that the caregivers lived with neither complete secrecy nor complete openness and that they staged disclosure about AIDS and their caregiving by carefully selecting certain amounts and types of information they wanted to reveal. The findings in this study support previous research that some women did not live with complete secrecy. Some women considered the risks and benefits of disclosing the HIV status to others. Those who needed emotional, financial, informational and tangible support disclosed their HIV status to other family members. On the other hand, women and their husbands who chose to keep the secret between themselves, were not in need of assistance or support from others. Powell-Cope and Brown's study (1992) report that AIDS family caregivers considered personal risks and benefits of going public. Similar potential risks reported in both studies were job discrimination and negative judgments. Potential benefits of gaining support and assistance form others were similarly reported in both studies.

Because most women in this study managed to keep their family's HIV status secret, they were isolated from their social circle and did not get needed social support. Similarly, the majority of HIV/AIDS caregivers in the study of Turner and colleagues (1994) expressed the feeling of loneliness. The evidence of HIV/AIDS caregiver's isolation is commonly documented in western literature (Hackl, Somlai, Kelly, Kalichmen, 1997; Stetz & Brown, 1997; Stewart, 1994). In Thailand, little research has been conducted to provide details about how this isolation and lack of support affects caregivers of PLWAs (Phengjard, 1998, Ruangjiratain, 2002; Songwathana, 2001).

Living with a time bomb referred to women's experience of time when they were waiting for their husband's death and, in some cases, their own death as well. HIV positive women described the feeling of not knowing how much time they and their husband had before they died. This experience is universal for HIV/AIDS caregivers (Brown & Powell-Cope, 1991; 1993). Brown and Powell-Cope (1991) described the uncertainty of survival HIV/AIDS caregivers experience when they do not know when death would occur. Living with loss and dying, caregivers revise their plans as needed for living in the world based on the possible and probable death of their care-receiver (Brown and Powell-Cope, 1993). In this study, participants did not revise their plans for living, but gave up planning for a future or making any long term commitments. Furthermore, women in this study described living as if their lives stopped going forward, but rather, had started counting backward toward death. Similar experience has been described in Thai literature (Treemanka, 1996).

Brown and Stetz (1999) identified caregiving tasks over the illness trajectory and found that caregiving tasks involved a wide range of activities that shifted from caring for the ill person to supporting someone who is dying, including managing the illness, negotiating the care needs, managing the environment, managing conflict, and preparing for death. Given the broad variations of the illness trajectories associated with HIV, the data from this study reflects a limited picture of caregiving tasks than those described in Brown and Stetz (1999), because there were no terminally ill husbands in this study. However, there are similarities in caregiving tasks between this study and other research on caregiving in people living with HIV/AIDS. These include: assisting with daily living (Phengjrad, 2001), dispensing medications (Janjarat, 1994; Jaruwat, 1997), symptom monitoring and management (Chunhapran, et al., 1992; Phengjrad, 2001; Stetz & Brown, 1997), health promotion (Phengjrad, 2001), and transporting to the hospital (Janjarat, 1994; Phengjrad, 2001). Caregivers in this study did not report performing advanced skills because their husbands were not terminally ill. However, caregivers in this study and other studies (Hoontrakool, 2001; Jaruwat, 1997; Phengjard, 2001) described that providing emotional support was the most important task because it enhanced emotional strength which could hen lead to increased physical strength of the PLWAs. Congruent with Phengjard's finding (2001), caregivers in this study were very involved in searching for and securing health care for their husband's, which reflected wives' involvement in making decisions relevant to of their husband's health care.

Caregivers of family members with other fatal illnesses are likely to expect the increasing caregiving demands over time as the disease progresses and as they prepare for caregiving in the terminal stage of the disease (Brown & Stetz, 1999). However, it was found that caregivers of PLWAs gave little attention to prepare themselves for future caregiving demands because they faced many unknowns over the course of illness (Brown & Powell-Cope, 1993). Similarly, many women in this study avoided thinking about their husband's terminal stage and did not plan for how they would handle a future of more intensive caregiving when their husbands become more ill. They did not project the increasing demands or difficulties of future caregiving or prepare themselves for end-of-life care. Therefore, terminal care is likely to be employed when it is required which may lead to difficulties in caregiving when women were unprepared and faced with unexpected situations. Not planning terminal caregiving may have been a way to emotionally survive their fear of death. Maybe they did not think about their husband's final phase of life, because they wanted to maintain hope that it would not arrive soon as it was too painful and frightening to think about. Although women in this study did not prepare for future caregiving, they were more likely to think about death and possessed different forms of preparation, including collecting material possessions for the well-being of family members they left behind. This reflects Thai cultural value that parents should leave behind the inheritance for their children to live comfortably after they die.

The study of HIV/AIDS caregivers in western countries support this study finding that the caregiving process began with the diagnosis of HIV/AIDS (Brown & Powell-Cope, 1992). Since wives were likely to be with their husbands when the diagnosis was made, or were told soon after, they were able to provide emotional care long before the need for physical care emerged. When their husbands were diagnosed with HIV/AIDS, the wives in this study encouraged and assured their husbands that they would stay with and care for them. This aspect of providing emotional care to husband's before the physical symptoms set in fills a gap in the HIV/AIDS caregiving literature in Thailand (Chunhapran, et al., 1992; Janjarat, 1994; Muecke, 2001; Phengjard, 2001; Songwathana, 2001). Thai research that has been done on HIV caregiving has mainly provided information about caregiving of significantly disabled and debilitated patients. The information found in this study contributes to HIV/AIDS caregiving literature in Thailand in demonstrating that wives took on the caregiving role as early as the diagnosis was made and that their caregiving began even before health of their husband's started to deteriorate

Constant changes are unique to HIV/AIDS family caregiving (Brown & Powell-Cope, 1991). Caregivers often experience uncertainty of AIDS-related symptoms where there are many ups and downs over the course of caregiving. The study findings support the concept of uncertainty described by Brown and Powell-Cope (1991). In this study, women experience ups and downs in caregiving because their husbands were sick with multiple illnesses and transitioned went back and forth between sickness and health. Women in this study, particularly, described their caregiving in terms of calm times when their husbands' health was good and their daily lives were more stable versus the times when husbands became ill and their lives were interrupted by the caregiving it demanded.

One of the strategies women used in caring for their husbands was to assign them an identity of being a sick person, described in the data as a "sick identity". Identifying their husbands as sick helped wives more easily provide their husbands with the special attention and care they needed as this helped them to cope with the new person their husbands had become. For example, women could more easily endure the aggressive behavior or emotional irritation that occurred knowing it was because their husbands were sick, viewing it as a part of a sick person's symptoms. Other studies (Jaruwat, 1997; Phengjard, 2001) described similar situations of caregivers dealing with changes in emotional status and behaviors of PLWAs. Most caregivers understood that these personality changes were a result of the disease, thus they were more patient and more able accept it. Because the nature of HIV disease consisted of a series of illnesses and progressively declining health over time, women lowered their expectation to their new reality by setting new levels of husband's well-being. Women had lower expectations about their husband's and developed new ways of thinking about it; instead of well-being having to do with being about being cured, they hoped that he would not get sick; instead of thinking about recovering to a healthy level, they hoped he would not get worse; and from thinking about being able to function normally, they hoped he could perform some activities of daily living. This concept of adapting new ways of thinking about well-being, depending on the circumstances, was a way that husbands and their wives could maintain a sense of hope in face of such overwhelming despair. This process of lowering expectations and changing one's perspectives as illness progressed have not been previously documented in Thai literature.

The preparation for death reported in the literature are activities that supported the structures around dying, including making wills, obtaining legal and financial services, and making funeral arrangement (Stajduhar, 1997; Stetz & Brown, 1997). Although the types of activities the participants in this study engaged in as they were preparing for death were different than the western research described, the purpose of preparing for death in this study was similar in that it occurred to help circumvent potential problems with family members who would be left behind. When women and their husbands learned about their HIV infection, they began preparing for death by building financial security for their children and planning for their future care. Similar findings were found in another study conducted with married couples with HIV positive female spouses (Kongsuriyanawin, 1997). In that study, couples made a plan for their future together regarding caregiving, finances, childrearing, and support.

Wives in this study reported that there were multiple responsibilities involved in caregiving, including raising children, earning income, maintaining the household, and in some cases, caregiving of elderly parents or sick children. Songwathana (2001) found similar findings. Her research further demonstrated that wives who are sick from HIV related illnesses were also responsible for caregiving for themselves, children living with HIV/AIDS and responsible for earning an income to support their extended family. The literatures confirmed that the burden and distress of female caregivers are greater than male caregivers because of their multiple roles in the society (Bruyn, 1992; Hackl, et al., 1997; Turner et al., 1994; Ward & Brown, 1994).

In this study, HIV negative women took risks of contracting HIV from their husband through sexual relationship and administering care. Women were fearful of contracting HIV from sexual contact with their husbands even though they used condoms. Kongsuriyanawin (1997) have reported similar evidence regarding fear of sexual transmission of HIV negative spouse. HIV negative husbands of wives living with HIV/AIDS had fears of HIV infection when having sexual relationships with their wives. Participants in both studies similarly expressed their lack of confidence in the effectiveness of condoms.

One of the new findings found in this study was that wives reported that they received emotional rewards from their caregiving. Seeing their husband's health improve and receiving praises from husbands and others created feelings of happiness, pride, appreciation, mental strength, and merit. This information contributes to the HIV/AIDS caregiving literature in Thailand which primarily demonstrates the negative effects of HIV/AIDS caregiving.

HIV negative women suspend their life and postpone their future in order to focus on caregiving of their husband. Education and carrier advancement, caring for elderly parents, parenting children, planning for the future were suspended until the caregiving responsibility was over. This finding is parallel to what sibling caregivers reported in Phengjard's study (2001). Sibling caregivers were forced to postpone their life goals, such as having their own families, to focus on caregiving. Western literature further supports the phenomenon of putting the future on hold to care for PLWAs by postponing short and long term plans and personal goals to devote themselves primarily to caregiving. (Brown & Powell-Cope, 1993).

HIV/AIDS caregivers often avoided specific mental images of their future caregiving activities, particularly during the final phase of the PLWAs life, such as, taking one day at a time and living fully in the moment (Brown & Powell-Cope, 1993). The strategies women in this study used in getting through their most difficult times confirmed the findings of pervious studies. Being fearful of death, they tended not to plan for or think about the end of their husbands life, but tried to live day by day, and live their life to the fullest.

Findings from this study are consistent with the literature of HIV/AIDS caregiving in Thailand that demonstrate that caregiver's physical and psychological health was affected by the caregiving (Phengjard, 2001; Ruangjiratain, 2002; Songwathana, 2001). Research on

HIV/AIDS caregiver in western countries also support that caregivers' health is negatively affected by the demand of caregiving (Flaskerud, & Tabora, 1998; Wight, LeBlanc, & Aneshensel, 1998). Physical exhaustion was common among HIV/AIDS caregivers in this study and other studies (Brown, McDaniel, & Birx, 1995; Folkman, et al., 1994). Findings form this study are consistent with the literature on AIDS caregiving that demonstrate that caring for PLWAs produce stress and strain for family caregivers (Brown, 1993; Brown, McDaniel, & Birx, 1995; Pearlin, Aneshensel, & LeBlance, 1997). The data revealed that women suffered psychologically in the form of stress, strain, burnout, and depression while they care for their sick and dying husbands.

Meaning of Caregiving

One of the study aims is to fill the gap in Thai literature concerning the meaning of HIV/AIDS caregiving. The purpose of a grounded theory investigation is to develop theory in regard to the meanings people place on events in the context of social interaction. The accounts of the wife caregivers in this study provide the meaning of HIV/AIDS caregiving. According to the women's accounts, HIV/AIDS caregiving represented a woman's sense of love, warmth, care, sympathy, attachment, companionship, duty and obligation for her. It was purposeful caring action to save and extend their husband's lives. The care performed aimed at maintaining and restoring husbands' well-being as well as eliminating physical and emotional suffering. The type of care they provided included physical and emotional care. Emotional care they provided also included staying in the relationship and taking the risk of HIV infection by meeting the sexual needs of husband. In addition, meaning of HIV caregiving was associated with a Buddhist belief of merit in the way that giving care was merit making. On the negative side, caregiving was perceived as a fruit of wives' karma, as well as husband's karma, which their wives bore the brunt.

By interviewing mothers, wives, husbands, and friends who are caregivers of PLWAs, Phengjard (2001) illuminated the meaning of caregiving as a symbol of love that family members had for each other and as a function of the family unit with the objective of caring, comforting, and protecting its vulnerable members. The meaning of caregiving defined in this study not only supports the meaning defined in Phengjard's work, but further expands it. In this study, caregiving not only represented the affectionate senses such as love, attachment, sympathy, etc., but it also represented a sense of social duty and obligation women had for their husbands. This may be because wife caregivers are socially and culturally tied to this role and responsibility of wife (Pradubmook, 1999), thus, how they view caregiving reflects Thai social and cultural values.

Regarding the objective of caring in Phengjard work, the women in this study had a different objective. They perceived the caregiving as a means to save and extend the life of their husband. Women in this study regarded their caregiving as important for their husband's survival. Due to the fact that caregivers in this study are wives, the meaning of caregiving in this study is rather specific to the context of wife's caregiving compared to those of Phengjard's study. Wives perceived that caregiving included staying to care, and for some, meeting their husband's sexual needs by risking HIV infection.

Contributing Factors of Sacrifice

Thai socio-cultural values about the role of women to care for husband's and children's well being, was an important factor that contributed to how women sacrificed to provide care to their husbands. Influenced by such values, wives perceived a sense of duty and obligation to provide care (Pradubmook, 1999; Songwathana, 2001). Some wives in this study provided care because they perceived it as their duty. Some wives provided care because of their sense of love, attachment, and loyalty to their husbands. Again, this perception is culturally constructed. Thai married women value love, attachment and loyalty toward their husbands (Choopraphawan, 1997). Thus, they are more likely to stay in relationship with their husband and care for them.

The second factor that contributed to women's sacrifice to caregiving of husband is the concept of karma. Buddhists religious beliefs have always been an integral part of Thai culture. Its values influences how Thai people view their world. Wife caregivers in this study believed that their suffering from HIV/AIDS and caregiving was the result of their karma (consequence of one's own past action), thus they should accept their suffering and responsibly of caregiving. Similar to other studies with Thai caregivers (Janjarat, 1994; Songwathana, 2001), karma provides caregivers with a way of coping with their suffering. Believing in karma enabled caregivers to get through the suffering and reach the state of acceptance of their caregiving responsibility.

In summary, this study portrays the life of wives caring for their husbands living with HIV/AIDS. This study identifies the basic social processes of the wife caregiving experience: sacrifice. The social process of sacrifice included staying to care, giving up, and enduring the struggle and represents the experience of Thai women caring for their husbands living with HIV/AIDS. Their experience is shaped by socio-cultural values of the Thai culture. The results of this study demonstrate the difficulties in caring for sick and dying husbands and address the need for supporting the caregiving efforts of the wives of PLWAs.

Implications for Future Research

The conceptual model generated in this grounded theory should be extended, refined and advanced to enhance its denseness and gain more explanatory power. It is suggested that the grounded theory study be conducted with wife caregivers in different contexts. For example, further research may include HIV wives who are also sick while caring for their sick husband, who are too sick to continue caring for their husbands, who are pregnant or have an HIV positive child, and who are the source of HIV infection themselves.

Since the findings of this study suggest that PLWAs' illness factors influence wife's experience, the concepts and their relationships merit further exploration in future research with wife caregivers of PLWAs across the illness trajectory to advance the understanding of HIV/AIDS caregiving. In this study, the conceptual model and the core category of sacrifice are derived from wives who choose to stay with their husband to provide care; future research should be directed at exploring the experience of wives who have no opportunity to choose between leaving and staying because of financial dependency or family and social reputation.

Given the various types of women caregivers in Thailand, grounded theory research is needed to provide theoretical understanding of the experience of other female HIV/AIDS caregivers in Thailand such as mothers, sisters, and female relatives/female friends/partners. The similarities and differences in the caregiving experience between these women caregivers should be identified to guide the appropriate intervention for each group. Additionally, grounded theory investigation should be conducted to describe the experience of husband caregivers whom Thai society does not highly regard and to see whether the processes identified by wife caregivers emerge or there are other processes involved in the caregiving provided by husbands.

These findings suggest that wife caregivers are affected by their current caregiving after their husband's death in terms of depleted financial resource, loss of spouse/family leader/provider, and the exposure of wives to HIV. Further grounded theory investigation should be undertaken with former wife caregivers who are now AIDS widows in order to gain more understanding about how HIV/AIDS affected wife caregivers after the death of their husbands. In addition, since this study investigates the wives who stayed in the relationship and accepted their caregiving responsibilities, it might be interesting to study wives who leave the relationship and refuse to care for their husbands.

According to these findings, there were several concepts specific to some HIV negative women that need further development and refinement, such as taking risks of getting HIV infection and giving up their opportunity to live, and being labeled as HIV positive just because they live with an HIV positive husband. Studying these concepts with a larger and more diverse sample of HIV negative wife caregivers is necessary in order to provide a better understanding of this experience so that specific interventions can be planned to match their needs.

The conceptual model generated from this study offers one theoretical explanation of HIV/AIDS caregiving. More theory should be generated to enhance and clarify the concept of HIV/AIDS caregiving in Thailand.

Implications for Nursing Practice

This emergent grounded theory contributes to nursing practice because it provides insights about the difficulties of women caring for their husbands living with HIV/AIDS.

Thai society, as well as health care professionals in Thailand, are likely to take wives caregiving for granted. This study shows that wife caregivers need support in providing care for their husbands. For nurses and other heath care providers, the study findings can create awareness of the important role of wives in caring for PLWAs and the way they care for their husbands. Through this understanding, nurses and other health care providers can assist wife caregivers in improving their quality of life and sustaining their commitment to care.

Information from this study is useful for those who work with PLWAs and their families in helping them gain insight and understanding of the experience of wife caregiver in Thailand. It is crucial that nurses recognize the difficulties wife caregivers experience and include them in their plan for care and nursing interventions.

Nurses can assist women in coping with the emotional distress caused by learning about HIV diagnosis and unfaithfulness of their husbands. If needed, counseling sessions should be designated for wives and husbands to discuss their feelings of anger and guilt related to the source of infection and helping them effectively solve their emotional conflicts.

In addition, nurses can help women make informed decisions regarding HIV testing, plans for caregiving and HIV prevention for themselves and other family members, and to help them cope with illness and pending death of their husbands or of themselves. Nurse should encourage HIV positive women to properly take care of themselves and their health needs while caring for their husbands. Women should be motivated to continue proper HIV care even though they are asymptomatic.

These findings demonstrate that some women do not use condoms to protect themselves from HIV. To prevent HIV transmission between HIV discordant couples, nurses should assess husbands' and wives' attitudes toward condom use as HIV prevention. A proper care strategy can be provided when there is a risk of HIV transmission through sexual contact. Knowledge about HIV disease and its transmission should be given to both wives and husbands in order to help them adjust to living with HIV and continue their sexual relationship as safely and normally as possible. Education programs should emphasize the importance of using precautions such as gloves and condoms. Nurse should encourage HIV negative women to continue monitoring their HIV status by occasionally having an HIV test repeated.

Based on the experience of the participants in this study, HIV negative women fear contracting HIV from their sexual relationships with their husband because of lack of confidence in condom use. The existing counseling services and educational programs should respond to this problem by focusing on helping these women learn about sexual prevention strategies in order for them to gain confidence in the preventive actions and have less fear of contracting HIV. Some women and their husbands perceived that condoms symbolize alienation between husbands and wives. It is necessary that nurses assess the couple's attitude toward condom use and motivate the couple to protect themselves by giving new meanings of condom use to promote its use between husband and wife.

Data from this study also suggests that women were emotionally rewarded by performing care to their husbands. This information could be helpful to the provision of counseling services to promote more positive outcomes of caregiving.

As this study illustrates health care support is needed to help wife caregivers cope with the stress and strain of caregiving and living with HIV/AIDS themselves. It is important that nurse assess the condition of wives and husbands and their caregiving needs across the illness trajectory. For example, in the early stages of HIV, wives may need emotional support to cope with the HIV diagnosis, disclosure, isolation, discrimination; and informational support to prevent HIV transmission. Later in the course of illness, there are needs for additional caregiving and emotional support to cope with their husbands pending death or their own deteriorated health and illnesses. Continuous assessment would assist nurses in identifying the services needed at each stage and then develop and implement appropriate plan of care for them. Home care services should be implemented for wives caring for PLWAs. Assisting in transition from hospital care to home care should be highlighted.

Nurses can develop outreach programs to gain access to wives of PLWAs who do not seek HIV test or HIV care for themselves. The program should focus on identifying wife caregivers of PLWAs, and reaching out to them while assuring confidentiality, offering easy access to medical, nursing, and counseling services. Nurses should extend their care to help wife caregivers cope with loss and grief of their husbands. Assisting HIV negative women with their transition from being a caregiver to an AIDS widow should be highlighted in nursing care plans.

Implications for Public Policy

The study findings suggest implications for public policy in several areas: public education and media campaign, caregiver support for home care, financial support, and anti-discrimination policy.

Public Education and Media Campaign Regarding HIV/AIDS

Changing the community perceptions about wives' risk of HIV, condom use between husbands and wives, community living with PLWAs, and HIV care seeking should be a priority in the public education policy and mass media campaign.

The findings suggest that wives are not as aware of the risk of contacting HIV from their husbands as they need to be. HIV/AIDS prevention campaign in Thailand should emphasize wives' risk of HIV/AIDS and focus on changing public perception about condom use to prevent HIV infection between husbands and wives. Though community education and mass media campaign, the public should be educated to increase awareness about the possibility that some wives of PLWAs may be HIV negative, so the public would not assume that they are HIV positive and discriminate against them; and wives themselves, should not assume their HIV infection without having an HIV test and ignoring the importance of protecting herself from contracting HIV from their husbands. However, the message must be present to the public with great caution so that it will not create a false sense of safety or contradict existing HIV prevention campaigns.

PLWAs fear discrimination and exposure of their HIV status. PLWAs and their families are not able to overcome the strong prejudice against HIV/AIDS. They need the larger public and private media and information institutions to make the message that PLWAs are not bad people; PLWAs and their families can live with others in the community; and they need support from the society to live with dignity as a human-being. It is necessary that institutions that create mass media take responsibilities and leadership in creating messages that change public perceptions concerning living with and supporting PLWAs and their families in the community.

Because of the current prejudice against PLWAs, they often delay or avoid seeking HIV care. PLWAs need to be informed about the benefit of early treatment, so that they seek early treatments and have a better chance stopping the progression of HIV disease. Through community education, the massage that "HIV treatment is available and with that treatment, a PLWA can live normally for a period of time" should be disseminated to the public to encourage PLWAs to seek care. Information about HIV/AIDS health care service available should be widely given to the public through the mass media. The current perception that HIV/AIDS equals death must be changed; and the new messages that a person can live with HIV when they receive early and proper HIV care, should be delivered through the mass media.

Caregiver Support for Home Care

Existing home/community care programs such as home care and home visit, need to include caregiving support and provide education for patients and caregivers with state of the art materials on caregiving concerns related to HIV, including such things as home infection control, progression of disease, symptom management, medication monitoring, and family respite. Any agency or institution involved in care in the home needs to make the caregiving education and dissemination of educational materials a priority. They need to distributed these materials unduly and be openly seen by the community as an easy resource for HIV/AIDS caregiver information. Caregiving support programs should be developed in health care settings and need to include caregiver support groups as a resource for informational and emotional support for caregivers of PLWAs.

Financial Support Systems

Systems to provide financial support to HIV/AIDS affected families need to be enlarged. Public policy makers need to include the economic effect of the epidemic on individual families as well as the Thai economy in general. Financial devastation is becoming the norm for families facing HIV. Protective financial mechanisms need to be created so that families do not have to exhaust all of their resources. This may include programs that generate family income, unemployment benefits, special HIV care benefits, or other mechanisms designed to ease family's financial burden. This needs to be available in every community, to any family facing HIV/AIDS. Although the medications and treatments for HIV related illnesses are covered by the basic health insurance, antiviral medications are not covered. Antiviral medications need to be included in existing Thai basic health insurance coverage to increase access to antiviral medications.

Anti-discrimination Policy

Discrimination happens when Thailand is affected by HIV/AIDS epidemic. Public policy needs to be developed to provide protection from discrimination. Anti-discrimination policy, particularly in work places, needs to be implemented in Thailand. These policies need to protect: (1) PLWAs who want to continue working; (2) caregivers who want to continue working either full or part time; (3) caregivers who want to take a leave of absence and does not want to loose their jobs; and (4) no services normally provided should be interrupted when an individual or family is affected by HIV.

Ethical Considerations and Sensitive Research Topics

Because of potential harmful social reactions toward PLWAs and their families if their HIV status was exposed to the public, participant's confidentiality is the most important issue in HIV/AIDS research. Guided by the western IRB regulations, the researcher in this study carefully designed the interview guide so that it was culturally appropriate and reflected cultural appropriate practices in Thailand to better provide protection of participants' confidentiality. Some common practices in the western country such as signing the consent, giving out a copy of the consent form, and telephone contact were adjusted to use with Thai populations. For example, taped recording verbal consent was used instead of signing if the participants were illiterate. Because the title of the study shown in the consent form can expose their HIV status, participants were given a choice to leave their copy of signed consent form with the researcher. Although it is common practice and appropriate in western countries to have potential participants contact the researcher if they are interested, to avoid involuntary participation, it is appropriate to offer the participants an opportunity to have the researcher contact them in person while they are at the clinic because it is less burdensome and possesses less risk of exposure for some women. In fact, the majority of women preferred to have the researcher contact them in-person while they are at the clinic because it was considered the most convenient and safe way to participate in the study. Because there were several individuals involve with the data, extra measures was used to assure confidentiality of participants, such as, using a confidentiality agreement form with the people involved with the data, such as local consultants, translators, and reviewers.

Because the study involved two institutions, the researcher was required to seek approval from both IRBs and follow both IRB regulations, which had different concerns and requirements on the research process. For example, the protocol for child and elder abuse is required in the US, but not in Thailand. The researcher had to give the Thai IRB's document to the OHSU IRB to demonstrate that Thai law does not require reporting of child and elder abuse. Although Thai IRB had their own consent form format, the researcher had to follow OHSU format and ask for the agreement from Thai IRB to use the OHSU format and words. As both IRB's requirement, the Thai version of OHSU English consent form had to be evaluated and approved by the Thai IRB as being translated correctly and culturally appropriate before using with Thai subjects. OHSU IRB needed to receive approval from Thai IRB before granting their approval. The Thai IRB required that the study have a physician sponsor who worked in the clinic to provide access and monitor subject recruitment before granting their approval. The researcher went through several extra steps to meet both IRB requirements, and spent a significant amount of time communicating and negotiating with the two IRBs. The two institutions worked collaboratively to find the best solution that suited the researcher and the international study circumstances.

In addition, the research findings illuminated some negative perspectives regarding Thai culture and practice, such as, men's double sexual standard and social discrimination against PLWAs. The potential threat to the reputation of Thai men and the country is a concern when the study findings are published internationally. The publication of the study findings will be presented in a way that does not disparage, but rather illuminate, the context from which the findings were interpreted, in order to maximize the benefits of the study rather than to damage the reputation of Thai men and the country. Meanings are imbedded in context and through placing those meanings with a contextual interpretation; the findings need to be understood within a Thai culture, rather than through a western culture. This research is needed for the advancement of HIV/AIDS knowledge in Thailand and better understanding of the wife's caregiver experience should lead to more culturally appropriate and responsive interventions. Even though the unpleasant facts may be told, it should not be done to disparage, but rather, to benefit Thai society.

Limitations

Because of certain characteristics of the Thai sample, transferability of the findings may be limited. Participants in this study were healthy caregivers. Although there were nine HIV positive women in the study, all of them were in the asymptomatic stage or early symptomatic stage of HIV with minor illnesses. Thus, they were able to devote themselves to providing care for their husband and maintaining family functioning. Additionally, none of them had HIV infected children or were pregnant. All of them contracted HIV from their current husbands who contracted HIV through heterosexual contacts with other women. All of the participants had opportunities to leave the relationship, but chose to stay with and care for their husband. Therefore the conceptual model does not reflect the experience of wife caregivers: (1) who were ill themselves while caring for their husband; (2) who had an HIV infected child; (3) who contracted HIV from injecting drug use, commercial sex, and ex-partners; or (4) who had no choice to leave the relationship or refuse to be a caregivers of their husbands.

Given the nature of the clients in the outpatient clinic, there is a disproportionate number of husbands across the HIV/AIDS illness trajectory. The majority of husbands were symptomatic but in relatively fair health, never having been hospitalized. Two of them were asymptomatic, and none were in the terminal stage of AIDS. Due to this disproportionate sample, the concepts sacrifice, caregiving, and outcomes may not have been sampled for maximum variation since the sample did not include wives of terminally ill husbands and had few wife caregivers of HIV asymptomatic husbands. In addition, because the data were collected from the hospital and clinic which provides western medicine, the findings from this study do not represent the perspective of women whose husbands sought alternative care outside of western medicine or those whose husbands did not seek health care at all.

The findings of this study represent only one account of the experience of Thai heterosexual women who were the primary caregivers of their husbands. These data do not include the perspective of HIV husband care-receivers, or the perspectives of other family members. Since the caregiving of PLWA's affect all family members, the voices of other family members may provide more insight into this phenomenon. Since these data were gathered, interpreted and conceptualized from within a Thai cultural perspective, the application of these findings are not appropriate for women outside Thai culture. Although these findings do not fully explain the phenomena of HIV/AIDS caregiving within the Thai family, they illuminate some aspects of this complex phenomenon.

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APPENDIX A

ANNOUNCEMENT FLYER

Announcement Flyer

At a clinic visit, the designated clinic staff will distribute the announcement flyer below to women who are female spouse caregivers of PLWAs receiving services from the HIV/AIDS clinic at the hospital setting. Those who are interested in participating will be given an opportunity to choose between giving verbal permission for the researcher to contact them, or contacting the researcher themselves by phone. If a woman prefers to have the researcher contact her, she will be asked by a clinic staff person verbally for permission of how and when to be contacted by the researcher.

SEEKING PARTICIPANTS

FOR A RESEARCH STUDY ENTITLED:

Experience of Thai Women Caring for Their Husband Living With HIV/AIDS

PRINCIPAL INVESTIGATOR:	Supinda Ruangjiratain, RN, MS Doctoral Student, School of Nursing Oregon Health & Science University
RESEARCH ADVISOR:	Judith Kendall, RN, PhD Professor, School of Nursing Oregon Health & Science University

This study is about understanding what it is like for wives caring for their husbands living with HIV/AIDS. The researcher is interested in learning about wives' caregiving experience at home. This study does not involve an experimental treatment or intervention given to patients or caregivers, but is solely an interview. An example of an interview question is: What is your typical day like when you are caring for your husband?

The study will involve at least one meeting, from 1-2 hours in length, at a place mutually convenient to you and the researcher. Regardless of the location, your privacy will be assured to the best of the researcher's ability. All information will be confidential and will not be shared with your husband, doctors, nurses, and others without your consent. Neither the name nor identity of the participants will be used for publication or publicity purposes.

Your decision to participate or not participate in this study will not affect any aspect of care or services you receive from this hospital. There will be no cost to you for participating in the study. You will be offered 800 Baht (US $20) per interview as compensation of your transportation costs.

If you are interested in participating in this study, you can either verbally give the clinic staff person a permission of how and when to be contacted Supinda Ruangjiratain, or you can contact her later by phone at 02-412-6024.

If you would like to learn more information about this study, please do not hesitate to call Supinda Ruangjiratain at 02-412-6024.

เอกสารแนะนำโครงการวิจัย

เจ้าหน้าที่ของคลินิกโรคติดเชื้อและภูมิคุ้มกันบกพร่องจะเป็นผู้แจกเอกสารฉบับนี้ ให้แก่ภรรยาที่ดูแลสามีที่ติดเชื้อเอชไอวี/ป่วยเป็นเอดส์ที่บ้าน ขณะมารับบริการที่คลินิก

ต้องการหาอาสาสมัครเข้าร่วมการวิจัย

เรื่อง

ประสบการณ์ของผู้หญิงไทยที่ดูแลสามีที่ติดเชื้อเอชไอวี/ป่วยเป็นเอดส์

ผู้วิจัย: นาง สุพินดา เรืองจิรัษเฐียร นักศึกษาปริญญาเอก
มหาวิทยาลัยโอเรกอนเฮลท์แอนด์ซายน์ ประเทศสหรัฐอเมริกา

ผู้ควบคุมการวิจัย: ศาสตราจารย์ จูดิท เคนดัล อาจารย์ คณะพยาบาลศาสตร์
มหาวิทยาลัยโอเรกอนเฮลท์แอนด์ซายน์ ประเทศสหรัฐอเมริกา

ท่านได้รับเชิญให้เข้าร่วมการวิจัยนี้ เพราะท่านเป็นภรรยาที่ดูแลสามีที่ติดเชื้อเอชไอวี/ป่วยเป็นเอดส์ที่บ้าน ผู้วิจัยสนใจที่จะเรียนรู้เกี่ยวกับชีวิตและประสบการณ์ของภรรยาที่เป็นหลักในการดูแลสามีที่บ้าน การวิจัยนี้ไม่เกี่ยวข้องกับการทดลองด้านการรักษาหรือยาของผู้ป่วยแต่อย่างใด แต่เป็นการวิจัยที่เกี่ยวข้องกับการสัมภาษณ์ภรรยาผู้ดูแลสามีที่ติดเชื้อเอชไอวี/ป่วยเป็นเอดส์ที่บ้าน ตัวอย่างของคำถามที่ใช้ในการสัมภาษณ์ ได้แก่ ชีวิตประจำวันของท่านเป็นอย่างไร เมื่อท่านดูแลสามีที่ติดเชื้อเอชไอวี/ป่วยเป็นเอดส์ที่บ้าน?

หากท่านเข้าร่วมการวิจัยนี้ ท่านจะถูกสัมภาษณ์อย่างน้อย 1 ครั้ง กินเวลาประมาณ 1-2 ชั่วโมง ในสถานที่ที่ท่านและผู้วิจัยเลือก ผู้วิจัยมีมาตรการที่จะเก็บข้อมูลของท่านเป็นความลับ และจะไม่เปิดเผยให้สามีของท่าน หมอและพยาบาลที่ดูแลสามีของท่าน และคนอื่นๆทราบสิ่งที่ท่านให้สัมภาษณ์ โดยไม่ได้รับความยินยอมจากท่านก่อน นอกจากนี้ ชื่อและข้อมูลส่วนตัวของท่านจะถูกเก็บเป็นความลับ และไม่ถูกนำไปตีพิมพ์หรือแผยแพร่สู่สาธารณะ

การเข้าร่วมหรือไม่เข้าร่วมในการวิจัยนี้ จะไม่มีผลกระทบต่อการดูแลหรือบริการที่ท่านและสามีได้รับจากโรงพยาบาลนี้ หากท่านปฏิเสธที่จะเข้าร่วมวิจัยนี้ ท่านและสามียังสามารถมารับบริการที่โรงพยาบาลนี้ได้ตามปกติ ในการเข้าร่วมการวิจัยนี้ ท่านไม่ต้องเสียค่าใช้จ่ายใดๆ แต่ท่านจะได้รับเงิน 800 บาท เพื่อชดเชยค่าเดินทางมาสัมภาษณ์แต่ละครั้ง

ถ้าหากท่านสนใจที่จะเข้าร่วมการวิจัยนี้ ท่านสามารถเลือกที่จะให้ผู้วิจัยติดต่อท่าน โดยให้ข้อมูลเกี่ยวกับ วัน เวลาและวิธีการติดต่อตัวท่าน ให้แก่เจ้าหน้าที่ที่ให้เอกสารนี้แก่ท่าน หรือท่านสามารถติดต่อผู้วิจัย คุณสุพินดา เรืองจิรัษเฐียร ด้วยตนเอง ทางโทรศัพท์ ที่เบอร์ 02-412-6024 หรือทางไปรษณีย์ ที่ 161/582 ซอยบุปผาสวรรค์ ถ. จรัญสนิทวงศ์ บางกอกน้อย กทมฯ 10700 ถ้าท่านต้องการทราบข้อมูลเพิ่มเติมเกี่ยวกับการวิจัยนี้ กรุณาสอบถาม คุณสุพินดา เรืองจิรัษเฐียร ที่เบอร์ 02-412-6024

APPENDIX B

CONSENT FORM

IRB# 7419
Approved:________

OREGON HEALTH & SCIENCE UNIVERSITY
INSTITUTIONAL REVIEW BOARD
CONSENT FORM APPROVAL DATE:
OCT 22 2002
[redacted]
APPROVED BY
PHONE NUMBER (503) 494-7887

OREGON HEALTH & SCIENCE UNIVERSITY

Consent Form

TITLE: Experience of Thai Women Caring for Their Husband Living with HIV/AIDS

PRINCIPAL INVESTIGATOR:	Supinda Ruangjiratain, RN, MSN	02-412-6024
CO-INVESTIGATOR:	Judith Kendall, RN, PhD	503-494-3890
	Linda Robrecht, RN, DNSc	503-494-3832
	Catherine Salveson, RN, PhD	503-494-3558
RESEARCH SPONSOR:	Department of Preventive Medicine Faculty of Medicine-Siriraj Hospital Mahidol University	02-411-5034

PURPOSE: You have been invited to take part in this study because you are a wife who is the primary caregiver of your HIV infected husband. The purpose of the study is to learn more about what the lives of women who are caring for their HIV infected husband are like. If you chose to take part in this study, you will have one or two interviews with the researcher, Supinda Ruangjiratain. There will be approximately 20 women like you participating in this study.

PROCEDURE: This study is being done at Siriraj Hospital. If you decide to take part, each interview will take 1-2 hours.

1. You will be interviewed at least one time. The interview will last 1-2 hours. You and the

researcher will choose where to do the interview together. During the interview, you will be asked questions about what it is like to care for you husband at home. The interview will be audiotaped and later transcribed. The tapes will be kept until all transcriptions are done and then destroyed.

2. At the end of the first interview, you may be asked to participate in the second interview approximately two to four weeks later. At the second interview the researcher will go over what you said at the first interview to make sure she has understood what you meant to say.

RISKS AND DISCOMFORTS: Some of the interview questions may seem very personal or embarrassing and may upset you. You may refuse to talk about a particular or confidential subject or answer any of the questions that you do not wish to answer. At any time during the interview, if you wish to stop the interview, the researcher will do so. If you become so upset by the questions that you appear to need counseling, we will help you find a counselor.

BENEFITS: You may or may not personally benefit from participating in this study. However, by serving as a research participant, you may contribute new information, which may benefit other women caring for HIV infected husbands in the future.

ALTERNATIVES: You do not have to take part in this study. No one will be angry with you if you chose not to. You and your husband can keep coming to the clinic as usual whether you take part or not.

CONFIDENTIALITY: Measures will be taken to assure confidentiality of your information to the best of the researcher's ability. You will be assigned a code name, which will not identify you. The code name will be recorded in the demographic forms and interview transcripts. All identifiable information mentioned in the interviews such as the names of persons, institutions, and locations, will be removed from the interview transcripts, thereby making it impossible to link the information from the interview transcripts back to you. Neither your name nor your identity will be used for publication or publicity purposes. All information will be confidential and will not be shared with your husband, his doctors, nurses, or others without your consent. Audiotapes, interview transcripts, and computer disks will be secured in locked cabinets during the course of study. These data materials will be kept for five years for use in future related research, except the recorded audiotapes, which will be destroyed at the end of the study. Research records may be reviewed and/or copied by the Oregon Health & Science University Institutional Review Board.

COSTS: There are no costs to you for taking part in this study. You will be offered 800 Baht (US$ 20) for each interview to help with the cost of coming to the interview.

LIABILITY: The Oregon Health & Science University is subject to the Oregon Tort Claims Act (ORS 30.260 through 30.300). If you suffer any injury or damage from this research project through the fault of the University, its officers or employees, you have the right to bring legal action against the University to recover the damage done to you subject to the limitations and conditions of the Oregon Tort Claims Act. You have not waived your legal rights by signing this form. For clarification on this subject, or if you have further questions, please call the OHSU Research Support Office at 0011-503-494-7887.

PARTICIPATION: The researcher, Supinda Ruangjiratian, will answer any questions you may have about this study. Supinda Ruangjiratain can be reached at 412-6024. If you have any questions about your rights as a research participant, you may contact the Oregon Health & Science University Research Support Office at 0011-503-494-7887 or The Ethical Committee on Human Rights Related to Research Involving Human Subjects, Faculty of Medicine Siriraj Hospital, Mahidol University at 411-1429, or 411-3253. You may be removed from the study if you cannot do the interviews. You may decide to quit being in the study at any time. If you choose to withdraw from this study, there will be no effect on your relationship with Siriraj Hospital or treatments, services, and benefits you and your husband receive at the hospital. You will be given a copy of this consent form.

SIGNATURES: Your signature below indicates that you have read the foregoing and agree to participate in this study.

Participant: ______________________________ Date: ____________________

Principal Investigator: ______________________ Date: ____________________

IRB # 7419
วันที่อนุมัติ: 22 ตค. 2545

มหาวิทยาลัย โอเรกอน เฮลท์ แอนด์ ซายน์ ยูนิเวอซิตี้
แบบหนังสือยินยอมเข้าร่วมการวิจัย

ชื่อโครงการวิจัย: ประสบการณ์ของผู้หญิงไทยที่ดูแลสามีที่ติดเชื้อเอชไอวี/ป่วยเป็นเอดส์

หัวหน้าโครงการวิจัย:	นาง สุพินดา เรืองจิรัษเฐียร, พยาบาลวิชาชีพ, วทม	02-412-6024
ผู้ร่วมวิจัย:	ดอกเตอร์ จูดิท เคนดัล, พยาบาลวิชาชีพ	503-494-3890
	ดอกเตอร์ ลินดา โรแบรค, พยาบาลวิชาชีพ	503-494-3832
	ดอกเตอร์ แคทเธอรีน ซาลวีซัน, พยาบาลวิชาชีพ	503-494-3558
ผู้สนับสนุนโครงการวิจัย:	ภาควิชาเวชศาสตร์ป้องกันและสังคม คณะแพทยศาสตร์ศิริราชพยาบาล มหาวิทยาลัยมหิดล	02-411-5034

วัตถุประสงค์ของการวิจัย: ท่านได้รับเชิญให้เข้าร่วมในการวิจัยนี้ เพราะว่าท่านเป็นภรรยาซึ่งเป็นผู้ที่เป็นหลักในการดูแลสามีที่ติดเชื้อเอชไอวีที่บ้าน การวิจัยนี้มีวัตถุประสงค์เพื่อทำความเข้าใจเกี่ยวกับชีวิตของผู้หญิงที่ดูแลสามีที่ติดเชื้อเอชไอวีว่าเป็นอย่างไร หากท่านเลือกที่จะเข้าร่วมในการวิจัยนี้ ท่านจะถูกสัมภาษณ์ 1 หรือ 2 ครั้ง โดยผู้วิจัย คือคุณสุพินดา เรืองจิรัษเฐียร ประมาณว่าจะมีผู้หญิงเช่นเดียวกับท่าน อีกประมาณ 20 คน เข้าร่วมในการวิจัยนี้

ขั้นตอนการวิจัย: การวิจัยนี้จะทำที่โรงพยาบาลศิริราช หากท่านตัดสินใจที่เข้าร่วมการวิจัย การสัมภาษณ์แต่ละครั้งจะใช้เวลาประมาณ 1 ถึง 2 ชั่วโมง

1. ท่านจะถูกสัมภาษณ์อย่างน้อย 1 ครั้ง การสัมภาษณ์จะกินเวลาประมาณ 1 ถึง 2 ชั่วโมง ท่านและผู้วิจัยจะเลือกสถานที่ที่จะสัมภาษณ์ด้วยกัน ในระหว่างการสัมภาษณ์ ท่านจะถูกถามคำถามเกี่ยวกับประสบการณ์การดูแลสามีของท่านที่บ้านว่าเป็นอย่างไร การสัมภาษณ์จะถูกบันทึกเทป และถอดความในภายหลัง เทปนั้นจะถูกเก็บไว้จนกว่าจะถูกถอดความ หลังจากนั้นจะถูกทำลาย

2. ในตอนท้ายของการสัมภาษณ์ครั้งแรก ผู้วิจัยอาจจะขอให้ท่านให้สัมภาษณ์เป็นครั้งที่สอง ในอีกประมาณ 2 ถึง 4 อาทิตย์ถัดมา ในการสัมภาษณ์ครั้งที่สองนี้ ผู้วิจัยจะถามเกี่ยวกับสิ่งที่ท่านพูดถึงในการ

สัมภาษณ์ครั้งแรก เพื่อให้แน่ใจว่าผู้วิจัยเข้าใจในสิ่งที่ท่านพูดอย่างถูกต้อง

ความเสี่ยงและความไม่สะดวก: คำถามที่ใช้ในการสัมภาษณ์บางคำถาม อาจดูเหมือนเป็นเรื่องส่วนตัว หรือเป็นเรื่องที่น่าอาย และอาจทำให้ท่านรู้สึกโกรธ ท่านอาจจะปฏิเสธที่จะพูดคุยเกี่ยวกับเรื่องบางเรื่อง หรือเรื่องที่เป็นความลับส่วนตัวของท่าน หรือ ตอบคำถามใดๆที่ท่านไม่ต้องการที่จะตอบ เมื่อใดก็ตามในระหว่างการสัมภาษณ์ ถ้าท่านต้องการที่จะหยุดให้สัมภาษณ์ ผู้วิจัยจะปฏิบัติตามความต้องการของท่าน หากท่านรู้สึกไม่สบายใจมาก จากคำถามที่ใช้ในการสัมภาษณ์ จนดูเหมือนว่าท่านจำเป็นต้องได้รับการให้คำปรึกษา ผู้วิจัยจะช่วยให้ท่านได้พบกับผู้ให้คำปรึกษา

ประโยชน์: ท่านอาจจะได้รับหรือไม่ได้รับประโยชน์โดยตรงจากการเข้าร่วมการวิจัยนี้ อย่างไรก็ตาม การเป็นอาสาสมัคร ท่านอาจจะมีส่วนช่วยในการให้ข้อมูลใหม่ๆ ซึ่งอาจจะเป็นประโยชน์กับผู้หญิงคนอื่นๆที่ดูแลสามีที่ติดเชื้อเอชไอวี/ป่วยเป็นเอดส์ ในอนาคต

ทางเลือก: ท่านไม่จำเป็นต้องเข้าร่วมในการวิจัยนี้ จะไม่มีใครไม่พอใจท่าน หากท่านเลือกที่จะปฏิเสธการเข้าร่วมวิจัย ท่านและสามีของท่านสามารถที่จะมารับบริการที่คลินิกนี้ตามปกติ ไม่ว่าท่านจะเข้าร่วมการวิจัยหรือไม่

การเก็บรักษาความลับ: จะมีมาตราการเพื่อประกันว่าข้อมูลของท่านจะถูกเก็บเป็นความลับ อย่างสุดความสามารถของผู้วิจัย ท่านจะได้รับชื่อรหัสที่จะไม่บ่งชี้ว่าเป็นท่าน และชื่อรหัสนี้จะถูกใช้ในแบบฟอร์มข้อมูลส่วนตัวและบทบันทึกการสัมภาษณ์ ข้อมูลทั้งหมดที่สามารถเชื่อมโยงไปถึงตัวท่าน เช่น ชื่อของบุคคล สถาบัน และสถานที่ จะถูกตัดออกจากบทบันทึกการสัมภาษณ์ ทำให้ไม่สามารถเชื่อมโยงข้อมูลจากบทบันทึกการสัมภาษณ์ไปถึงตัวท่านได้ ชื่อหรือข้อมูลส่วนตัวของท่านจะไม่ถูกนำไปตีพิมพ์ หรือเผยแพร่สู่สาธารณะ ข้อมูลทั้งหมดจะถูกเก็บเป็นความลับ และไม่ให้สามีของท่าน หมอ พยาบาลที่ดูแลสามีของท่าน หรือบุคคลอื่นๆ โดยไม่ได้รับ ความยินยอมของท่านก่อน เทปบันทึกเสียง บทสัมภาษณ์ และแผ่นเก็บข้อมูลคอมพิวเตอร์ จะถูกเก็บไว้อย่างปลอดภัยในตู้ล็อคกุญแจ ตลอดระยะเวลาการวิจัย เอกสารข้อมูลทั้งหมดถูกเก็บไว้ประมาณ 5 ปี เพื่อใช้ในการวิจัยที่เกี่ยวข้องในอนาคต ยกเว้นเทปบันทึกเสียงจะถูกทำลายเมื่อสิ้นสุดการวิจัย บันทึกผลวิจัยอาจจะถูกพิจารณาและ/หรือถ่ายสำเนา โดยสถาบันพิจารณาการวิจัยในคน มหาวิทยาลัย โอเรกอน เฮลท์ แอนด์ ซายน์ ยูนิเวอซิตี้

ค่าใช้จ่าย: ท่านไม่ต้องเสียค่าใช้จ่ายใดๆในการเข้าร่วมวิจัยนี้ ท่านจะได้รับเงินค่าตอบแทน จำนวน 800 บาท ต่อการสัมภาษณ์แต่ละครั้ง เพื่อชดเชยค่าใช้จ่ายในการเดินทางมาสัมภาณ์

ความรับผิดชอบ: มหาวิทยาลัยโอเรกอน เฮลท์ แอนด์ ซายน์ ยูนิเวอซิตี้ อยู่ภายใต้พระราชบัญญัติชดเชยการละเมิดสิทธิโอเรกอน (Oregon Tort Claims Act) (ORS 30.260 ถึง 30.300) ถ้าท่านได้รับบาดเจ็บ หรือ ความเสียหายใด ๆ จากการวิจัยนี้ โดยที่ปืนความผิดของมหาวิทยาลัย เจ้าหน้าที่ หรือพนักงานของมหาวิทยาลัย ท่านมีสิทธิที่จะดำเนินการทางกฎหมายต่อมหาวิทยาลัย เพื่อเรียกร้องค่าชดเชยความเสียหายที่เกิดกับท่านได้ ภายใต้ข้อจำกัดและเงื่อนไขของพระราชบัญญัติชดเชยการละเมิดสิทธิโอเรกอน (Oregon Tort Claims Act) ท่านไม่ได้สละสิทธิทางกฎหมายโดยการเซ็นชื่อในแบบฟอร์มนี้ เพื่อความชัดเจนในเรื่องนี้ หรือหากท่านมีคำถามเพิ่มเติม กรุณาติดต่อไปยังสำนักงานสนับสนุนการวิจัย มหาวิทยาลัย โอเรกอน เฮลท์ แอนด์ ซายน์ ยูนิเวอซิตี้ (OHSU Research Support Office) ที่เบอร์โทรศัพท์ 001-1-503-494-7887

การเข้าร่วมวิจัย: ผู้วิจัย คือ คุณสุพินดา เรืองจิรัษเฐียร จะตอบคำถามใดๆที่ท่านอาจจะมีเกี่ยวกับการวิจัยนี้ ท่านสามารถติดต่อ คุณสุพินดา เรืองจิรัษเฐียร ได้ที่เบอร์โทรศัพท์ 02-412-6024 หากท่านมีคำถามใดๆ เกี่ยวกับสิทธิ ของท่านในฐานะอาสาสมัคร ท่านอาจจะติดต่อ สำนักงานสนับสนุนการวิจัย มหาวิทยาลัย โอเรกอน เฮลท์ แอนด์ ซายน์ ยูนิเวอซิตี้ (OHSU Research Support Office) ที่เบอร์โทรศัพท์ 001-1-503-494-7887 หรือ คณะกรรมการจริยธรรมการวิจัยในคน คณะแพทยศาสตร์ศิริราชพยาบาล มหาวิทยาลัยมหิดล ที่เบอร์โทรศัพท์ 02-411-1429, หรือ 02-411-3253 ท่านอาจจะถูกคัดออกจากการวิจัยหากท่านไม่สามารถให้สัมภาษณ์ได้ ท่านอาจจะตัดสินใจถอนตัวจากการวิจัยนี้ได้ตลอดเวลา หากท่านเลือกที่จะถอนตัวออกจากการวิจัยนี้ จะไม่มีผลกระทบต่อความสัมพันธ์ของท่านกับ โรงพยาบาลศิริราช หรือต่อการรักษา, บริการ และผลประโยชน์ที่ท่านและสามีของท่านได้รับจากโรงพยาบาลแต่อย่างใด ท่านจะได้รับแจกสำเนาแบบยินยอมเข้าร่วมวิจัยนี้เมื่อท่านยินยอมเข้าการวิจัย

ลายเซ็น: ลายเซ็นของท่านข้างล่างนี้แสดงว่าท่านได้อ่านข้อความข้างต้น และยินยอมเข้าร่วมการวิจัยนี้

ผู้เข้าร่วมวิจัย: ______________________ วันที่: ______________

ผู้วิจัยหลัก: ______________________ วันที่: ______________

APPENDIX C

INITIAL INTERVIEW GUIDE

Initial Interview Guide

Participants will be asked the following broad questions. Not all probes will be asked, but they will be used based on the information gained during the interview.

Tell me about your experience of caring for your husband?
Possible probes:

1) What is it like to take care of your husband living with HIV/AIDS?
2) Tell me what you feel about caring for your sick husband?
3) How do you feel about being a caregiver of your husband?
4) What make you decide to take care of your husband?
5) How do you feel about this decision now?
6) How does your caregiving affect you?
7) How has you role as wife change?
8) How does caregiving affect your health?
9) What are positive /negative about caring for your husband?

Tell me about your typical day when you are taking care of your husband?
Possible probes:

1) Please describe your typical day when you are caring for your husband?
2) What things are hard? What things are easy?
3) Tell me about things that you do for your husband when you care for him?
4) How does your caregiving affect your typical day?
5) How do you manage problems related to HIV/AIDS/caregivings?

Tell me about your husband/your HIV infection?
Possible probes:

1) How did you find out about your husband's/ your HIV status?
2) How do you feel about your husband having AIDS?
3) How do you see yourself (before and after the diagnosis)?
4) How do you feel about being HIV positive?
5) What is it like to contract HIV from your husband?
6) How did you feel when you know about his or your diagnosis?
7) What do you think of HIV/AIDS?
8) Whom do you tell about the diagnosis?
9) How do you disclose the diagnosis to others?
10) What are people's reaction after you told them about the diagnosis?
11) How does people (family, relative, friends, health care provider) treat you?

Tell me about your family?
Possible probes:

1) How does AIDS affect your family (physically, emotionally, financially)?
2) Tell me about your family relationship (before/after the diagnosis)?
3) How does AIDS affect your marital relationship?
4) Tell me what you feel about your husband impending death?
5) How does the death of your husband affect you?

Tell me about your life?
Possible probes:

1) What are your concerns or worries?
2) What are your needs?
3) How is your health?
4) What are your health concerns?
5) How is the health of your other family members?
6) What resources (people, facilities) do you use?
7) What kind of support did you have? From whom?
8) How do you cope with the your situation?
9) How do you view your future?
10) What do you plan for your life?

General Probing Questions:

1) How do you feel about….?
2) What is your thought/reaction to….?
3) How that make you feel…?
4) What do you mean by…?
5) Can you tell me more about…?
6) What make you feel….?
7) When does ….occur? What make ….occur?
8) Any thing you want to tell me or want to add?
9) What do you think about….?
10) Could you tell me why…?

แนวคำถามสัมภาษณ์

ผู้วิจัยจะถามคำถามกว้าง ๆ เพื่อให้อาสาสมัครมีโอกาสถ่ายทอดประสบการณ์จากมุมมองของตนเองมากที่สุด สำหรับคำถามเจาะลึกนั้น ผู้วิจัยจะเลือกถามเพียงบางคำถามขึ้นอยู่กับข้อมูลที่ได้รับจากการสัมภาษณ์

<u>คำถามกว้าง ๆ</u> กรุณาเล่าถึงเกี่ยวกับประสบการณ์การให้การดูแลสามีของคุณ

<u>คำถามเจาะลึก</u> 1) การดูแลสามีที่ติดเชื้อเอชไอวี/ป่วยเป็นเอดส์เป็นอย่างไร
2) กรุณาเล่าถึงความรู้สึกของท่านเกี่ยวกับการดูแลสามีที่ป่วย
3) ท่านรู้สึกอย่างไรเกี่ยวกับการเป็นผู้ดูแลสามีของท่าน
4) อะไรทำให้ท่านตัดสินใจดูแลสามีของท่าน
5) ในขณะนี้ ท่านรู้สึกอย่างไรเกี่ยวกับการตัดสินใจนั้น
6) การให้การดูแลมีผลกระทบอย่างไรกับท่าน
7) บทบาทภรรยาของท่านเปลี่ยนไปอย่างไร
8) การให้การดูแลมีผลกระทบอย่างไรกับสุขภาพของท่าน
9) การดูแลสามีของท่านมีข้อดีและข้อเสียอย่างไร

<u>คำถามกว้าง ๆ</u> กรุณาเล่าถึงชีวิตประจำวันของท่านตอนที่ท่านให้การดูแลสามีที่บ้าน

<u>คำถามเจาะลึก</u> 1) มีสิ่งใดที่ยากและมีสิ่งใดที่ง่ายในการดูแลสามีที่บ้าน
2) กรุณาเล่าถึงสิ่งที่ท่านทำให้สามีเวลาที่ท่านดูแลสามีที่บ้าน
3) การให้การดูแลมีผลกระทบต่อชีวิตประจำวันของท่านอย่างไร
4) ท่านจัดการกับปัญหาที่เกี่ยวข้องกับโรคเอดส์และการดูแลสามีของท่านอย่างไร

<u>คำถามกว้าง ๆ</u> กรุณาเล่าถึงการติดเชื้อของสามีของท่านและของตัวท่าน

<u>คำถามเจาะลึก</u> 1) ท่านรู้เกี่ยวกับสถานภาพการติดเชื้อของสามีของท่านและ/หรือของตัวท่านอย่างไร
2) ท่านรู้สึกอย่างไรที่สามีของท่านเป็นโรคเอดส์
3) ท่านมองตัวท่านอย่างไร (ก่อนและหลังการวินิจฉัยโรค)
4) ท่านรู้สึกอย่างไรกับการที่ท่านติดเชื้อเอชไอวี
5) ท่านรู้สึกอย่างไรกับการที่ท่านติดเชื้อเอชไอวีจากสามี
6) ท่านรู้สึกอย่างไรเมื่อท่านทราบเกี่ยวกับการติดเชื้อของสามีและ/หรือของตัวท่าน
7) ท่านคิดอย่างไรเกี่ยวกับโรคเอดส์
8) ท่านบอกใครบ้างเกี่ยวกับการวินิจฉัยโรค
9) ท่านบอกให้ผู้อื่นทราบเกี่ยวกับการวินิจฉัยโรคอย่างไร

10) คนอื่นๆ มีปฏิกิริยาอย่างไรเมื่อท่านบอกเกี่ยวกับการวินิจฉัยโรค

11) คนอื่นๆ (ครอบครัว, ญาติ, เพื่อน, เจ้าหน้าที่สาธารณสุข) ปฏิบัติต่อท่านอย่างไร

<u>คำถามกว้าง ๆ</u> กรุณาเล่าถึงครอบครัวของท่าน

<u>คำถามเจาะลึก</u> 1) โรคเอดส์มีผลกระทบต่อครอบครัวของท่านอย่างไร (ด้านร่างกาย, จิตใจ, เศรษฐกิจ)

2) กรุณาเล่าถึงความสัมพันธ์ในครอบครัวของท่าน (ก่อนและหลังการวินิจฉัยโรค)

3) เอดส์มีผลกระทบต่อความสัมพันธ์ระหว่างสามีภรรยาอย่างไร

4) กรุณาเล่าถึงความรู้สึกเกี่ยวกับความตายกำลังมาถึงของสามีของท่าน

5) การตายของสามีของท่านมีผลกระทบต่อท่านอย่างไร

<u>คำถามกว้าง ๆ</u> กรุณาเล่าถึงชีวิตของท่าน

<u>คำถามเจาะลึก</u> 1) ท่านมีความวิตกกังวลเกี่ยวกับเรื่องอะไร

2) ท่านมีความต้องการอะไรบ้าง

3) สุขภาพของท่านเป็นอย่างไร

4) ท่านมีความวิตกกังวลอะไรเกี่ยวกับสุขภาพของท่าน

5) สุขภาพของคนในครอบครัวของท่านเป็นอย่างไร

6) ท่านใช้แหล่งช่วยเหลืออะไรบ้าง (คน, สถานที่)

7) ท่านได้รับการสนับสนุนอะไรบ้าง จากใคร

8) ท่านเผชิญปัญหาในสถานการของท่านอย่างไร

9) ท่านมองอนาคตของท่านอย่างไร

10) ท่านวางแผนอะไรในชีวิตของท่าน

<u>คำถามเจาะลึกทั่วไป</u> 1) ท่านรู้สึกอย่างไรเกี่ยวกับ...........

2) ท่านมีความคิดหรือปฏิกิริยาอย่างไรเกี่ยวกับ...........

3) มันทำให้ท่านรู้สึก...........

4) ท่านหมายถึง...........

5) กรุณาเล่าให้ฟังอีกนิดเกี่ยวกับ...........

6) อะไรทำให้ท่านรู้สึก...........

7) ....เกิดขึ้นเมื่อไร อะไรทำให้เกิดขึ้น...........

8) มีอะไรที่คุณต้องการเล่าให้ฟังหรือต้องการเพิ่มเติม...........

9) ท่านคิดว่าอย่างไรเกี่ยวกับ...........

10) ท่านบอกได้ไหมว่าทำไม..........

APPENDIX D

DEMOGRAPHIC FORM

Demographic Form

To be filled out by the researcher based on self-report of participants via the interview.

	Wife	**Husband**
Age		
Education		
Occupation		
Employment status		
Monthly income		
# of years married		
# of family members______	Gender: ____________ Age:_________ Relationship:____________ Gender: ____________ Age:_________ Relationship:____________ Gender: ____________ Age:_________ Relationship:____________ Gender: ____________ Age:_________ Relationship:____________ Gender: ____________ Age:_________ Relationship:____________ Gender: ____________ Age:_________ Relationship:____________	
# of persons in the household ______	Gender: ____________ Age:_________ Relationship:____________ Gender: ____________ Age:_________ Relationship:____________ Gender: ____________ Age:_________ Relationship:____________ Gender: ____________ Age:_________ Relationship:____________ Gender: ____________ Age:_________ Relationship:____________ Gender: ____________ Age:_________ Relationship:____________	

	Wife	**Husband**
HIV status		
Mode of HIV transmission		
Opportunistic infections so far		
Date of HIV positive Dx		
Date of Dx of AIDS		
# of hospitalizations ______	Date:______Cause:___________ Date:______Cause:___________ Date:______Cause:___________	Date:______ Cause:___________ Date:______ Cause:___________ Date:______ Cause:___________
Medications		
Who knows about Dx?	Relationship:_______________ Reaction:______________________ Relationship:_______________ Reaction:______________________ Relationship:_______________ Reaction:______________________ Relationship:_______________ Reaction:______________________	

แบบฟอร์มข้อมูลส่วนตัว

(แบบฟอร์มนี้ สำหรับผู้วิจัยกรอกข้อมูลที่ได้รับจากคำบอกเล่าของอาสาสมัครในขณะสัมภาษณ์)

	ภรรยา	สามี
อายุ		
การศึกษา		
อาชีพ		
สถานภาพการทำงาน		
รายได้ต่อเดือน		
จำนวนปีที่แต่งงาน		
จำนวนสมาชิกครอบครัว______	เพศ_________อายุ_______ความสัมพันธ์_______________ เพศ_________อายุ_______ความสัมพันธ์_______________ เพศ_________อายุ_______ความสัมพันธ์_______________ เพศ_________อายุ_______ความสัมพันธ์_______________	
จำนวนสมาชิกในบ้านเดียวกัน_____	เพศ_________อายุ_______ความสัมพันธ์_______________ เพศ_________อายุ_______ความสัมพันธ์_______________ เพศ_________อายุ_______ความสัมพันธ์_______________ เพศ_________อายุ_______ความสัมพันธ์_______________	

	ภรรยา	สามี
สถานภาพการติดเชื้อเอชไอวี		
สาเหตุที่ติดเชื้อ		
โรคติดเชื้อฉวยโอกาสจนถึงขณะนี้		
วันที่ที่ทราบผลเลือดบวก		
วันที่วินิจฉัยโรคเอดส์		
จำนวนครั้งที่เข้ารับการรักษาในโรงพยาบาล______	วันที่_______สาเหตุ_______ วันที่_______สาเหตุ_______ วันที่_______สาเหตุ_______	วันที่_______สาเหตุ_______ วันที่_______สาเหตุ_______ วันที่_______สาเหตุ_______
ยาที่ได้รับ		
มีใครบ้างทราบเกี่ยวกับการวินิจฉัยโรค	ความสัมพันธ์_______________ปฏิกิริยา_______________ ความสัมพันธ์_______________ปฏิกิริยา_______________ ความสัมพันธ์_______________ปฏิกิริยา_______________ ความสัมพันธ์_______________ปฏิกิริยา_______________	

APPENDIX E

CONFIDENTIALITY AGREEMENT FORM

To assure participant's confidentiality, research consultants, dissertation committee, and a translator will be asked to sign a confidentially agreement form below.

Confidentiality Agreement Form

Experience of Thai Women Caring for Their Husband Living With HIV/AIDS

My signature below indicates that I understand and agree to the following:

I agree that I have been provided information and documents about this research for the purpose of data analysis or translation only. I understand the important of protecting the confidentiality of the research participants, all parties and agencies involving in this research. I also understand that I must keep all the information and documents provided in absolute confidence. Besides the principal investigator, I will not discuss or share any of the information and documents with anyone under any circumstances.

Name: ______________________________________

Position in the study: ___________________________

Signature: ___________________________________

Signature of principal investigator: ________________

Date: _______________________________________