# Stressors, Strengths, and Social Supports of Thai Families Caring for Persons Living with HIV/AIDS: A Pilot Study

By

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# ABSTRACT

TITLE: Stressors, Strengths, and Social Supports of Thai Families Caring for Persons Living with HIV/AIDS: A Pilot Study

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This qualitative study was designed to describe the experiences, from the perspectives of Thai families, of caring for persons living with HIV/AIDS (PLWAs). The specific aim was to identify perceived family stressors as well as family strengths and social supports which help Thai families to cope with the stressors. A case study with replication design was employed. The sample consisted of 10 families with diverse family types including nuclear, extended, and unconventional families. Semi-structured interviews were conducted with 31 participants which included the PLWAs, primary caregivers, and their family members. Genograms, ecomaps, and chart reviews were also used to collect the data. Qualitative content analysis was the method of analysis.

Family profiles were presented for better understanding of each family and its context. Data about family stressors, strengths, and social supports were analyzed across all families. Families experienced multiple stressors while caring for the PLWAs. Nine family stressors associated with HIV/AIDS were identified: financial burden, discrimination and rejection, concealing the HIV/AIDS diagnosis, caregiving tasks, caregiver's burnout, PLWA's uncertain health status, PLWAs' emotional suffering, struggling with the health care system, and planning for impending death. The families mobilized their abilities and resources to cope with the stressors. Nine family strengths were employed: religious beliefs, strong sense of family obligation, sense of forgiveness and understanding, emotional connection, receiving social support, maintaining hope, family working together, diverting attention from HIV/AIDS, and focusing on the present. It was found that the families described the receiving of social support as a family strength, and thus it was included in that concept.

A better understanding of the experiences of Thai families regarding stressors, strengths, and social supports of Thai families caring for PLWAs, provides useful information for health care providers and policy makers to improve health care services and develop effective interventions to support the families caring for persons living with HIV/AIDS.

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# CHAPTER 1

# INTRODUCTION

Human Immunodeficiency Virus (HIV) disease is both an individual and a public health problem. HIV is an infectious disease, which causes the immune system to become severely damaged. When clinical conditions progress to include opportunistic infections and neoplasms, it becomes the Acquired Immunodeficiency Syndrome (AIDS). Currently, there is no cure.

The wide spread incidence of HIV/AIDS in Thailand has become a serious concern. The HIV/AIDS epidemic began in Thailand in 1984. Through the year 2000, 984,000 Thai people have been infected with HIV, which represents nearly 1.6% of the total population. Of those, approximately 300,000 people have already died from AIDS (AIDS Division, 2001a). At present, close to 30,000 new infections occur each year. It is projected that 50,000 people will die from AIDS each year within the next five years. (AIDS Division, 2001a). Seventy five percent of persons living with HIV/AIDS are in the age range of 25-44 years; male to female ratios are 3.5 to 1 (AIDS Division, 2001b).

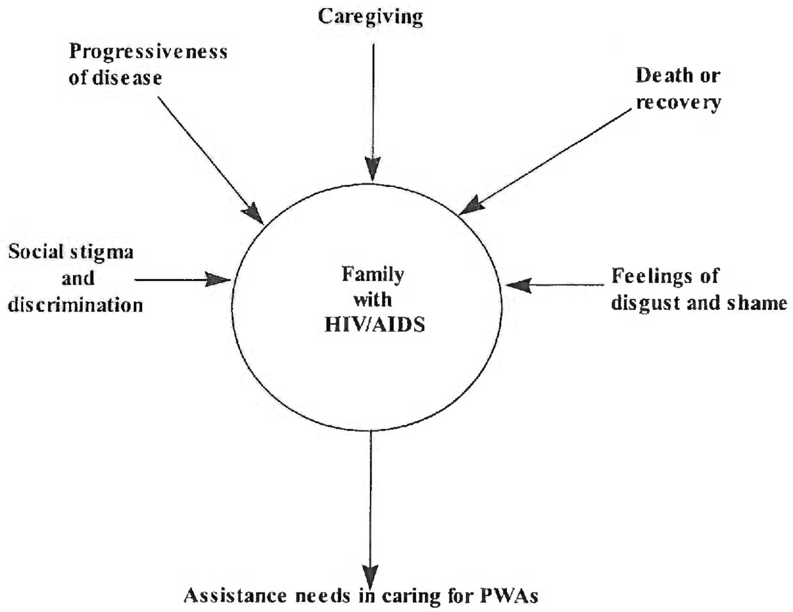
In the Thai AIDS population, sexual intercourse is the leading route of transmission (83 %). Most of HIV transmissions are through commercial sex. Intravenous drug use is the second leading route of transmission (5 %), followed by transmission of HIV from infected mothers to their babies (4 %) (AIDS Division, 2001b).

Approximately three-quarters of a million people in Thailand currently are living with HIV/AIDS, which creates a great demand for health care (AIDS Division, 2001a). The institutional facilities soon will not be able to care for all AIDS patients due to the increasing number of "persons living with HIV/AIDS" (PLWAs). It is expected that the health care costs to care for institutionalized AIDS patients will increase dramatically.

The family is now expected to be the main provider of care for these individuals when they are discharged from a hospital. Over the course of the illness, PLWAs move back and forth between being active and having an opportunistic infection. Families are required to provide care and deal with the possibility of death as well as the possibility of recovery. The crisis created by the HIV infection profoundly impacts the families who are called upon for care. Health care services need to incorporate and assist families in caring for PLWAs. Currently there is no comprehensive home-based care program to assist families living with an HIV/AIDS member in providing care at home.

The nature of HIV/AIDS transmission relates to culturally unacceptable behaviors such as prostitution, homosexual behavior and drug use. These behaviors leads to stigmatization, disdain, feelings of shame and difficulty in accepting persons living with HIV/AIDS. Formerly, the mass media about HIV/AIDS in Thailand used scary tactics. This led to misperceptions and misunderstandings that caused undue fear and a sense of shame within families and communities (Songwathana & Manderson, 1998). The PLWAs and their families are subject to rumors and stigma that are devastating if the disease is publicly revealed. Thai cultural norms and lifestyles suggest that families, relatives and friends have strong bonds and cohesiveness and take care of each other when sickness occurs. Taking care of PLWAs is an exception. Having and taking care of a member with HIV/AIDS causes crisis and stress in Thai families (see Figure 1). They not only have to deal with the physical challenges but also with the psycho-sociological challenges resulting from the disease.

*Figure 1.* Crisis and stress in families caring for someone with HIV/AIDS.



Most studies about families living with HIV/AIDS have been conducted with Caucasian-American families. Little is known about the effects of HIV/AIDS on Thai families who have a different social and cultural context surrounding the disease. Therefore, research is needed and this pilot study will help meet the need. The stress on Thai families when living with a member with HIV/AIDS, the strengths they use to help them cope, and the supports they have to deal with this situation need to be explored. The purpose of this study is to identify the stressors, strengths, and supports of Thai families who are caring for someone with HIV/AIDS and to understand these families' experiences. The findings will assist nurses in providing care to these families and provide the investigator with definitive data for further research. Ultimately the results will guide policy makers in initiating educational and home-based care programs in Thailand to meet the needs of people with HIV/AIDS and their families.

# CHAPTER 2

# CONCEPTUAL BACKGROUND

This chapter presents the conceptual background used in this study. First, the concept of family is discussed. Next, the conceptual framework for the study is presented. Family Systems Theory and the Family Assessment Intervention Model were used to guide the conceptual framework. Last, the concepts of interest (i.e. family stressors, family strengths, and family social support) are described.

## Concept of Family

There are several definitions of "family". The traditional definition for family came from Burgess and Locke, (1953 as cited in Hanson, 2001a). The "family" used to be "a group of persons united by ties of marriage, blood, or adoption, constituting a single household; interacting and communicating with each other in their respective social roles of husband and wife, mother and father, son and daughter, brother and sister; and creating and maintaining a common culture" (Hanson, 2001a, p. 4). This definition of "family" in the U.S. and Thailand has been the traditional definition, however does not cover the wide array of families today. A more recent definition of family is "two or more individuals who depend on one another for emotional, physical, and economic support. The members of the family are self-identified" (2001a, p. 4). Since people who are taking care of HIV/AIDS individuals may not be family members, as defined by the traditional definition of family, the latter is used in this study.

# Conceptual Framework

## *Family Systems Theory*

Hanson (2001a) described four different approaches to family nursing. First, *family as context* is the traditional approach, which focuses on the care of an individual client with the family as the context. Second, *family as a client* is the approach that focuses on the family as the focus of care, and all individual family members are assessed and receive care. Third, the *family as a component of society* approach views the family as one of the many institutions in society. Lastly, the *family as a system* approach views the family as an interactional system in which the whole is more than the sum of its parts. For the purpose of this study, the *family as a system* approach was used and Family Systems Theory served as the conceptual background for this study.

Based on the assumptions of Family Systems Theory, a system is composed of a set of interacting elements; each system can be identified and is distinct from the environment in which it exists. Systems have boundaries that can be open, closed or random (Friedman, 1998b). This approach focuses on the individuals and their family simultaneously, concerning the interactions between family members (Hanson, 2001a). Clients are seen as participating members of a family (Hanson & Kaakinen, 2001). The central notion of Family Systems Theory is that family systems are greater than, and different from, the sum of their parts. Family systems change constantly in response to stresses and strains from inside and outside the system, and a change in one part of the system affects other parts of the system (Hanson & Kaakinen, 2000). In this sense, the entire family affects the family members; in turn, family members affect the entire family. For instance, the illness of one or more family member(s) affects all other members of the family. Nurses apply this perspective to assess the effects of an individual's illness upon the entire family system and the effects of the family on an individual's illness (Wright & Leahey, 2000).

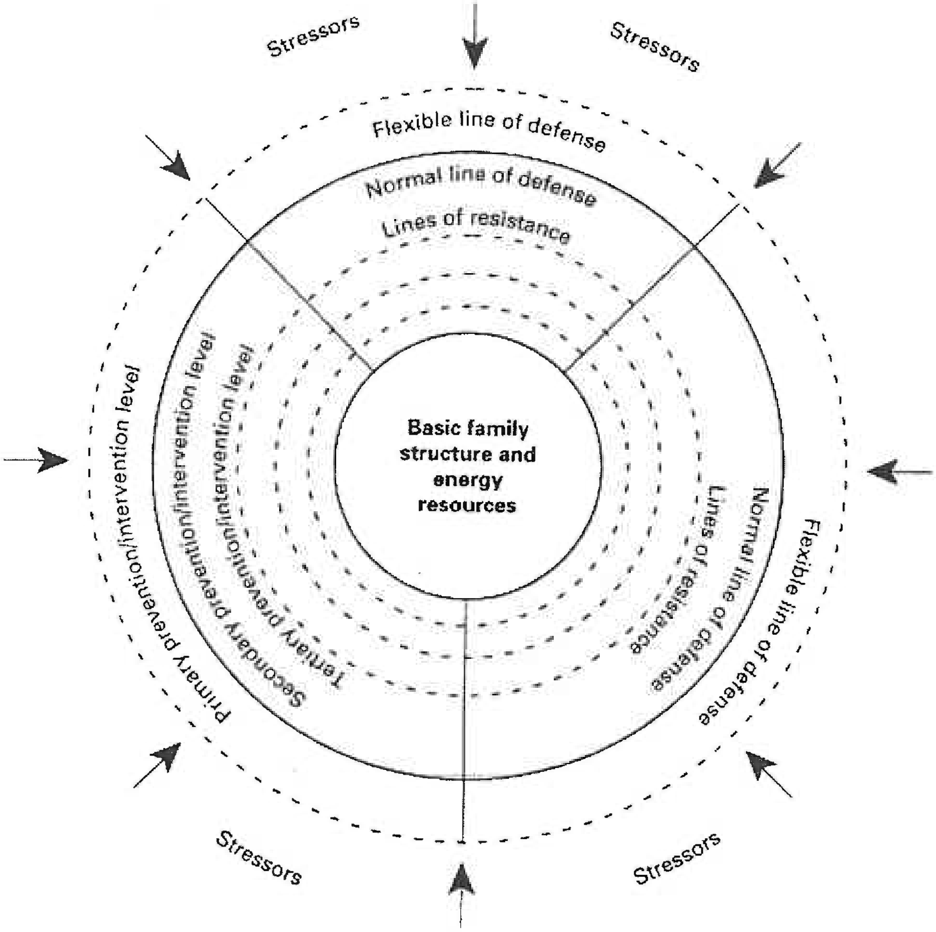
There are many nursing models in nursing literature that have been used as a conceptual framework. The family Assessment Intervention Model was selected to serve as the conceptual framework for this study because it was developed with the Family Systems Theory providing its central approach.

### *Family Assessment Intervention Model*

Berkey and Hanson (1991) took Betty Neuman's Health Care System Model that was developed for individuals, and further developed the model to apply to families. This conceptual model explicates the interaction between family systems and their environments and is based on the concepts of stress and reaction to stress. The Family Assessment Intervention Model is diagrammed in Figure 2.

Two of the three basic concepts explored in this study are derived from the Family Assessment Intervention Model-- family stressors and family strengths. Family stressors are defined as "the problems, conditions, or situations that are capable of causing family instability and threaten family functioning capability and health" (Hanson & Mischke; 1996, p. 172). The other concept, family strengths, is defined as "the abilities and resources which families use to solve problems and cope with stressors" (Hanson & Mischke, 1996, p. 179).

*Figure 2.* Family Assessment Intervention Model.



*Note.* From *Family assessment and intervention* (p. 173), by S. M. H. Hanson, 2001b. In S. M. H. Hanson (Ed.), *Family health care nursing: Theory, practice, and research.* (2nd ed.), Philadelphia: F. A. Davis. Copyright 2001 by F. A. Davis Company. Reprint with permission of the author.

According to the Model, the family is viewed as an open and dynamic system, which interacts with its environment, and is subjected to tensions created by stressors, which exist in the family's environment in the forms of problems, conditions, or situations that could produce instability within the family system. The family system is a *core* surrounded by protective concentric circles. The protective circles surrounding the family core act as a protective buffer system to protect the family core from the stressors and maintain the stability of the family system. The protective circles are composed of normal and flexible lines of defense and lines of resistance. Normal line of defense refers to family's usual stability level or wellness state. The family system is protected by the flexible line of defense, which acts as a cushion against the stressors. A set of internal resistance factors known as "lines of resistance" functions to stabilize and return the family to the usual wellness state. Lines of resistance represent family strengths or abilities and resources which families use to solve problems and adapt to the stressful situations. The core is comprised of the family's basic structure that consists of the family's functions and energy resources. The family core must be protected if the family unit is to remain healthy and functional (Hanson, 2001b; Hanson & Mischke, 1996; Hanson & Kaakinen, 2000).

The family may be subjected to tension produced by stressors when they penetrate the family's defense system. Each stressor has different potential to disturb the family's normal stability or normal line of defense. The family system is protected by the flexible line of defense against environmental stressors. When the flexible line of defense is no longer capable of protecting the family system, the stressors break through and alter the family's usual functioning. At this point, the line of resistance or family strengths can provide protection by stabilizing and returning the family to the usual wellness state (normal line of defense). The family reacts to preserve or restore impaired family functions depending on the penetration of the stressors and the family's abilities to adapt to stressful situations or family strengths.

According to the Family Assessment Intervention Model, family functions, which are a part the family's basic structure within the family core, must be protected to maintain strength and healthiness of the families. Friedman (1998a) and Hanson (2001a) defined family functions as the ability of the family to satisfy the needs for both individual members and wider society. The assumption is that if family functions are strong and intact, families can assume the primary responsibilities of maintaining the health requirements of their family members. Thus, family functions must be protected when families are faced with stressors (Berkey & Hanson, 1991; Hanson & Mischke, 1996).

Family functions are vulnerable when family members have an illness or stressful situation. According to the concept of family health, the illness of family members influences family functions and causes problems and imbalances. Family functions are in a state of instability when a family member is ill (Chou, 1996). If the stressors start to impact normal family functioning, family strengths provide protection in maintaining the continuum of normal family life.

The concepts of family stressors and family strengths that are explored in this study are drawn from the Family Assessment Intervention Model discussed earlier. In addition to these concepts, family social supports are also explored in this study. Although Berkey and Hanson (1991) did not describe the concept of family social supports in their Family Assessment Intervention Model, family social supports appear to tie into the model. For the purpose of this study, the concept of family social supports is further incorporated into the conceptual model.

It is apparent that individuals and their families do not live alone, but exist in a social environment such as social networks. Stressful events are more likely to mobilize social networks and initiate the social support process. It is a common belief by several disciplines that social supports received from the social networks can alleviate the effects of stress and serve as a preventive strategy to reduce stress (Cohen & Syme, 1985; Friedman, 1998c; House, 1981). Based on this notion, social supports appear to mediate the impact of the stressors on the family systems. In this sense, social supports can be incorporated into Family Assessment Intervention Model as the family's resources that promote adaptation to the stressors in order to maintain family stability. As a result, the line of resistance (protective circle surrounding the family core) in the model is further conceptualized to compose both family strengths and family social supports. Therefore, the concept of family social supports is explored in this study.

In summary, the concepts of family stressors, family strengths, and family social supports are the focus of this particular study. The following sections discuss these three concepts. The definitions of each concept are also provided.

## Concept of Family Stressors

The basic assumption of the Family Assessment Intervention Model is that "many known, unknown, and universal environmental stressors exist, and each differs in its potential for disturbing a family's usual stability level" (Hanson, 2001b). Many families encounter not only the stressors that exist in daily family life but also the stressors associated with illness. Illness qualifies as one kind of stressor to the family (Danielson, Hamel-Bissell & Winstead-Fry, 1993; McCubbin & McCubbin, 1993). Because the family is the primary source of care for a sick member, an illness within the family affects the whole family and its interaction (Friedman, 1998a). When a family member becomes ill and is unable to fulfill usual tasks and roles, family functions are affected. The rest of the family members may face tension, stress or increased burdens in their roles. As a stressor, illness of family members can create instability in the family system. In this particular study, illness is viewed as a major stressor because the family system is influenced by its sick members. However, families are affected by more than one type of stressors: stressors related to the illness and stressors in the family daily life. Therefore, both types of family stressors were explored in this study.

According to the Family Assessment Intervention Model, family stressors were defined as "the problems, conditions, or situations that are capable of causing family instability and threaten family functioning capability and health" (Hanson & Mischke; 1996, p. 172). For the purpose of this study, this definition is adopted.

## Concept of Family Strengths

The concept of family strengths is derived from the strength-and wellness-orientation, which focuses on why some families are healthy and strong. Family strengths refer to caring, nurturing, and growth-facilitating qualities of individual family members that affect the interactive and relationship patterns of a family system (Berky & Hanson, 1991). When families encounter stressors, some families are able to mobilize their strengths and resources, and adapt effectively to stressful situations, while other families are not. Berkey and Hanson (1991) noted that not only family stressors should be identified, but also family strengths should be assessed to determine how families use their strengths and resources to gain, preserve, and maintain system stability. Therefore, the family strengths were explored in this study. For the purpose of this study, family strengths are defined as "the abilities and resources which are used by families to solve problems and cope with stressors" (Hanson & Mischke, 1996, p. 179).

## Concept of Family Social Supports

Although social support for individuals was well researched, little investigation of family social support was found (Kane, 1988; Roth, 1996). According to Kane (1988), family social support is viewed as enabling the family to function with versatility and resourcefulness, thus it promotes family health. Family is viewed as a system in which it engages in a process of interaction within itself and between itself and the environment. There is a flow of energy in terms of information, goods, services, and emotions within the family and between the family and its social networks. Social supports are viewed as a positive and helpful social process reflecting a pattern of interaction over time between the family and its social system. Kane (1988) defines family social support as "a process of relationship between the family and its social environment". For the purpose of this study, this definition of family social support is adopted because it is derived from the Family Systems Theory and the *family as a system* approach, and is consistent with the context of family faced with stressors.

Generally, the concept of family social supports concerns the two components: the structure of the relationship (social networks), and the function of the relationship (type of social support) (Cohen & Syme, 1985). Wortman and Conway (1985) suggested that the study of the structure of the relationship, such as social network information, is critical in research with physically ill individuals, because physical illness may alter their network structure. Assessment of the various types of social support is useful because different types of support may have different effects on a particular outcome. Therefore, two components of social support, family social networks and type of social supports, were examined in this study.

In conclusion, this chapter discussed the theory and model that served as the conceptual background for this study as well as the concepts that were explored—family stressors, family strengths, and family social supports. Figure 3 summarizes the definitions of the concepts.

*Figure 3.* Definitions of the concepts.

| | |
|---|---|
| Family | Two or more individuals who depend on one other for emotional, physical, and economical support. The family is self-defined by family members (Hanson, 2001a). |
| Family Stressors | The problems, conditions, or situations that are capable of causing family instability and threaten family functioning capability and health (Hanson & Mischke, 1996). |
| Family Strengths | The abilities and resources which are used by families to solve problems and cope with stressors (Hanson & Mischke, 1996). |
| Family Social Supports | A process of relationship between the family and its social environment (Kane, 1988). |

# CHAPTER 3

# REVIEW OF LITERATURE

This chapter presents a review of the research literature related to family and HIV/AIDS. This chapter also summarizes literature addressing general family stressors, strengths, and social supports.

## Family and HIV/AIDS

In this section, the research on family and HIV/AIDS is reviewed. The review of literature is discussed in three sections. The first section discusses the United States' experience. International experience in the developing world and Thailand's experience are discussed in the second and third sections.

### *The United States' Experience*

This section presents a review of the U.S. literature on family and HIV/AIDS. These studies include: HIV/AIDS related stressors, HIV/AIDS non-related stressors, and strengths of families with HIV/AIDS.

There has been much research on the family and HIV/AIDS. The majority of studies have considered the experience of families when their members have HIV/AIDS. Families experience the same emotional reactions as HIV/AIDS patients experience, such as shock, anxiety, anger, fear, guilt and depression (Bor 1990, 1992; Lippman, James & Frierson, 1993; Takigiku, Brubaker, & Hennon, 1993). All stresses that affect infected individuals also affect family members. The psychological impact of HIV/AIDS on the family has been broadly studied. There is substantial evidence that HIV/AIDS profoundly affects families including the relationships between family members and increase stresses within the family and between the family and other social systems (Bor, 1990, 1992; Bor, Miller, & Goldman, 1993; Aranda-Naranjo, 1993; Flaskerud, 1995).

Atkins and Amenta (1991) measured stress in persons with AIDS and their families compared to hospice patients and their families. They found that the scores for accumulated stresses in persons with AIDS and their families were significantly higher than those in hospice patients and their families. McShane, Bumbalo, and Patsdaugther (1994) conducted a study to describe the psychological distress of living with HIV/AIDS. Their findings showed that parents, siblings and people living with AIDS (PLWAs) had a three to four times higher level of overall distress and depression than a community-based sample of nonpatients. Whether or not family members are involved in direct caregiving, psychological distress is a predominant experience for family members. In sum, families who have a member living with HIV/AIDS present various psychological responses and experience high stress related to the disease. The number of stressors and level of stress increase when one changes from HIV-positive to AIDS (Semple, Patterson, Temoshok, McCutchan, Straits-Troster, Chandler, & Grant, 1993).

Studies about the family and HIV/AIDS expanded on certain stressors, both those related to HIV/AIDS and HIV/AIDS non-related stressors. The studies on each type of stressors are summarized in the following sections.

*HIV/AIDS related stressors.* The major emphasis of several studies is on the family's stressors, which related to their HIV/AIDS experiences. Problems and hardships arise directly from HIV/AIDS. Fear of contagion is one of the most frequent stressors related to HIV/AIDS. Almost everyone who has a family member with HIV/AIDS reports experiencing the fear of becoming infected. The persons living with HIV/AIDS also experience the fear of infecting others (Flaskerud, 1995; Giacquinta, 1989). In families with HIV infected women, fear and uncertainty of having an infected child through pregnancy or breast-feeding are significant stressors (Semple et al., 1993). The use of AZT during pregnancy and delivery has reduced the incidence of infection, however the stress remains.

Burden of caring for persons living with HIV/AIDS is another family stressor. Chronic poor health, ongoing medical treatment and hospitalization of a member cause high stress in families (Semple et al., 1993). Families encounter daily stressors associated with physical/ psychological condition and medical demands of the patient, including the complex management of the illness and caregiving issues (Chuncharus, Thanprasertsuk, Yachompoo, & Dechsiri, 1994; Chekryn, 1989; Schmidt, 1992). AIDS family caregivers experience significant amounts of stress related to the caregiving work. Caregiving to an HIV-positive spouse is described as highly stressful (Semple et al., 1993). The stressors associated with the demands surrounding caring for a family member with HIV/AIDS include the pressure of an altered relationship between the caregiver and the care receiver; potential danger of HIV/AIDS; and the mental, physical, and the emotional work of managing the sick person's illness on a daily basis (Brown & Powell-Cope, 1991; Brown, 1993; Powell-Cope & Brown, 1992).

The stigma of AIDS becomes a stressor for people living with HIV/AIDS and their family members (Frierson, Lippmann, & Johnson, 1987; McCain & Gramling, 1992; Semple, et al., 1993). The stigma of AIDS significantly affects the decision to disclose the HIV/AIDS diagnosis to others such as extended families, friends, and neighbors. Because of the stigma of

AIDS, an AIDS diagnosis was more likely to be hidden or kept as a secret (Serovich, Greene, & Parrott, 1992). It is stressful when families face major conflict about whether to disclose the diagnosis to others and which people to tell.

Social stigma related to AIDS creates negative reactions and rejection from others and society. PLWAs and families suffer rejection and discrimination from relatives, friends, and society. The discrimination and rejection due to the fear of contagion, sexual preference, and drug use augments the stress experienced by PLWAs and their families (Atkins & Amenta, 1991; Flaskerud, 1995; Giacquinta, 1989; Knox, Davis, & Friedrich, 1994). Caregivers also experience HIV/AIDS stigma in the form of rejection, loss of friends and harassment (Powell-Cope & Brown, 1992).

Lack of a support system is another stressor. The consequence of social stigma and rejection is that families lack the social supports they would normally receive when a family member has a life-threatening illness (Geis, Fuller, & Rush, 1986; Giacquinta, 1989; Ostrow, Whitaker, & Frasier, 1991; Takigiku et al., 1993). Geis, Fuller, and Rush (1986) found that significant stress derived from isolation from usual support networks. When the diagnosis is not disclosed to external support networks such as the extended family and friends, they are excluded from providing a supportive and normalizing experience for the family (Bor, et al., 1993). While Semple and colleagues (1993) found that spouses and extended family members were accepting and supportive of people living with HIV/AIDS, Atkins and Amenta (1991) found that there are fewer people in the families' social network due to the HIV/AIDS stigma and the fears emanating from its infectiousness.

Anticipatory dying and the loss of someone living with HIV/AIDS is another family stressor. Multiple and premature loss of a family member also is stressful. Since people living with HIV/AIDS are usually young, families feel that it is an untimely, undeserved and unjust illness and death (Bor, 1992; Flaskerud, 1995).

Financial problems are a common stressor (Atkins & Amenta, 1991; Semple et al., 1993). Because people living with HIV/AIDS are young, they have limited financial resources. Health-related unemployment contributes to financial strain in two ways: it reduces income and may cause loss of health insurance. Medical costs of HIV/AIDS related illness and other increased expenses cause the family economic hardships.

Maintaining employment is another stressor that surfaces as a result of HIV/AIDS (Semple et al., 1993). The fear of losing one's job is particularly stressful for persons living with HIV/AIDS. Persons living with HIV/AIDS reported that chronic fatigue resulted in a lack of stamina and loss of mental concentration on the job, frequent absenteeism, and lowered quality of work. Families also experience this stress as caring for the sick member requires losing time from work and may cause loss of job (Semple, et al., 1993).

In summary, the research about stressors related to HIV/AIDS included fear of contagion, disclosure of the diagnosis, caregiving burdens, social stigma and discrimination, lack of social supports, dying and loss, financial problems, and unemployment. These stressors affected both PLWA and family members.

*HIV/AIDS non-related stressors.* Normal stressful daily life events do not disappear when one becomes HIV-positive. Families also experience stressful life events that are unrelated to HIV/AIDS. These stressors have the potential to adversely affect family health and well-being. Little research has been studied of family daily life stressors in families caring for someone with HIV/AIDS. Semple and colleagues (1993) studied daily life stressors of HIV-positive women that surfaced. Family conflicts with teenage children and household chores were reported in this study. Marital relationship problems and termination (Fleskarud, 1995), communication problems (Mellins, Ehrhardt, Grant, Elkin, & DuBose, 1995), revelations of stigmatized life style such as drug use and sexual preference (Frierson, et al., 1987), neglect of the other children in family (Heagarty, 1991), child behavior and emotional problems (Roth, Siegel, & Black, 1994; Knox, et al., 1994), crime and legal issues, moving, health problems of other members (Semple et al., 1993) were daily life stressors for these families.

*Strengths in Families with HIV/AIDS.* None of the studies about stressors explored the strengths of families living with HIV/AIDS. However, several studies focused on coping strategies used by persons living with HIV/AIDS, their caregivers, and families to deal with the stressors created by HIV/AIDS. The studies related to this area are discussed next.

Evidence supported the notion that some families coped well with stressful situations caused by an illness; moreover some researchers examined the strategies used for coping with the stressful situations by HIV/AIDS patients and families. McCain & Gramling (1992) studied people diagnosed with HIV disease and found that coping assistance was provided through established support groups and family support, including partners. Coping included employing religious beliefs, living in the here-and-now, thinking positively, and avoiding preoccupation through staying busy, working, and using distraction such as television. Other coping strategies described in other studies included using denial, focusing on spiritual beliefs and faith, practicing open communication (Aranda-Naranjo, 1993), employing community identification, creating social activism, producing community AIDS education (Powell-Cope & Brown, 1992) and seeking social support networks (Aranda-Naranjo, 1993; Powell-Cope & Brown, 1992).

### *International Experience*

The international literature on HIV/AIDS and family is reviewed in this section. The impact of the HIV/AIDS on families, families' experiences, and the reaction of families vary with ethnicity, religion, race, and social class (Brown, 1997). Most previous research has been conducted on western families. The United States' experience of HIV/AIDS that does not apply to families in the developing world includes: (a) access to medical and nursing care; (b) availability of treatment and supplies; (c) support for individuals and families from organizations such as public health, home health; (d) knowledge base from research; and (e) resources which help AIDS patients such as Medicaid, disability, and public assistance. Because of these differences, it cannot be assumed that the research results of western families represent families in the developing world.

Most of the international literature is studies conducted in Africa, where there is the largest number of people living with HIV/AIDS. Most studies have focused on the HIV/AIDS epidemic. Limited attention has been given to families' experience when caring for someone with HIV/AIDS.

Caregiving is a major stressor for African families (Katabira, Keleeba, Sebbanja, Okurut, Kaseje, Anderson, Tembo, & Marum, 1994; Seeley, Kajura, Bachengana, Okongo, 1993). Caregiving was a responsibility of an individual family member, such as mother and spouse, with the limited assistance from relatives. The relatives refused to help with care because of the poverty and other commitments (Seeley, Kajura, Oknogo, Wagner, & Mulder, 1992). In the African culture, it is believed that the person who infected the patient should give the care, or the patient should give care to him/herself (Ankrah, Lubega, Nkumbi, 1989). This belief resulted in the limited assistance of care from relatives. Caregiving problems included the provision of special diets, physical care, transportation, medicines, and counseling (Ankrah, Schumann, McGrath, Gessa, Nkumbi, & Lubega, 1992).

Financial problems are another stressor. Lack of money for food and medication due to the poverty is common in African families (Seeley, et al., 1993). Most African families affected by HIV/AIDS are poor and cannot afford treatment, medicines and hospitalization.

Lack of support from relatives and social networks is also identified as a stressor (Seeley, et al., 1993; Ankrah, et al., 1989). Africans do not accept that their relatives suffer from HIV disease. They think the diagnosis is some other disease of witchcraft (Seeley, et al, 1992). This belief results in the limited support from relatives and the social networks.

### *Thailand's Experience*

This section presents a review of Thailand's literature on family and HIV/AIDS. Thailand is one of the developing countries facing the rapid spread of HIV/AIDS. Lack of health care facilities and services to assist families creates stress in families who are caring for members with HIV/AIDS.

Few studies have been conducted on Thai families. Stigma and discrimination due to the fear of contagion and feelings of shame are major stressors (Chuncharus, et al., 1994; Srichard, Chawon, & Luke, 1995). Financial problems are described as another stressor.

Financial problems result from the loss of income from the patient, expenditures for treatment, hospitalization, and other expenses such as transportation (Chuncharus, et al. 1994).

Caregiving is another stressor in Thai families (Chuncharus, et al., 1994; Srichard, et al., 1995). The stressors associated with caregiving practice included lack of knowledge/ skill to care for PLWAs, and lack of knowledge to protect themselves from exposure. Lack of caregiver support, medical supplies, and helping resources for families caring for members with HIV/AIDS at home was described as stressful (Bennett, Salazar, Williams, Himmavanh, & Charerntanyarak, 1994).

In conclusion, most stressors are similar among the three different cultures: the U.S., Africa, and Thailand. These stressors include stigma and discrimination, financial problems, and caregiving practices. The unique stressor in the developing countries is lack of support from relatives, social networks, and health care resources. Studies about strengths that families used to cope with the stressors were not available in the international or Thai literature.

## General Family Stressors, Strengths, and Social Supports

The families with HIV/AIDS encountered not only the stressors related to the disease process, but also the stressors that existed in the daily life of families. The information about general family stressors, strengths, and supports, which is one focus of this study, was not available in the international or Thai literature. There has been sparse research done on an international basis, or in Thailand, about general stressors, strengths, and supports in families.

In this section, only the U.S. studies that explored stressors that exist in daily family life, the strengths and the supports families used to deal with those stressors are reviewed.

### *Family Stressors*

A number of family researchers focused on family stressors that impair daily family life (Curran, 1985; Olson, McCubbin, & Associates, 1983). One of the most current studies is the work of Curran (1985). Curran, a family specialist, examined common stressors in normal family life. Four hundred-fifty men and women were asked to rank the top ten stressful situations that cause the most stress in their daily family life. The following is the result of the ranking: (a) economics/ finances/ budgeting; (b) children's behaviors; (c) insufficient couple time; (d) lack of shared responsibility in the family; (e) communication with children; (f) insufficient "me" time; (g) guilt for not accomplishing more; (h) spousal relationship; (i) insufficient family playtime; (j) overscheduled family calendar (p. 20). There are 25 common stressors identified by American families that induce harmful effects on normal family life listed in Figure 4.

### *Family Strengths*

Many family researchers enlarged the focus from family's stressors to include family strengths as well. These researchers have delineated the characteristics and behaviors of healthy families (Curran, 1983; Otto, 1973; Pratt, 1976; Stinnett & Defrain, 1985). One of the researchers who studied family strengths was Curran (1983). Curran's work focused on family traits that are considered family's strengths. By surveying professional groups who work with families, 20 traits of family strengths, believed to facilitate family stability and health, were

*Figure 4.* List of 25 common family stressors.

Economic/finances/budgets
Children's behavior/discipline/sibling fighting
Insufficient couple time
Lake of shared responsibility in the family
Communication with children
Insufficient me time
Guilt for not accomplishing more
Spousal relationship (communication, friendship, sex)
Over scheduled family calendar
Self-image/self-esteem/feelings of unattractiveness
Family member(s) feeling unappreciated

Perfectionism
Dieting
Health/illness
Housekeeping standards
Insufficient family playtime
Television
Moving
Holiday
In-law
New baby
Unhappiness with work situation
Overvolunteerism
Neighbors
Teen behavior

*Note.* From *Stress and the Healthy Family* (p. 17), by D. Curran, 1985, Minneapolis, MN: Winston Press.

*Figure 5.* List of 20 common family strengths.

- Communicates with and listens to one another
- Affirms and supports one another
- Teaches respect for others
- Develops a sense of trust in members
- Has a sense of play and humor
- Has a sense of shared responsibility
- Teaches a sense of right and wrong
- Has a strong sense of family in which rituals and traditions abound
- Has a balance of interaction among members
- Has a shared religious core
- Respects the privacy of one another
- Values service to others
- Fosters family table time and conversation
- Shares leisure time
- Admits to and seeks help with problems
- Honors its elders
- Accepts and encourages individual values
- Values work satisfaction
- Is Financially secure
- Able to let go of grown children

*Note.* From *Traits of a Healthy Family* (p. 23) by D. Curran, 1983, Minneapolis, MN: Winston Press.

identified and ranked. Figure 5 lists these traits. The top ten were: (a) communicates and listens; (b) affirms and supports one another; (c) teaches respect for others; (d) develops a sense of trust; (e) develops a sense of play and humor; (f) exhibits a sense of shared responsibility; (g) teaches a sense of right and wrong; (h) has a strong sense of family in which rituals and traditions abound; (i) has a balance of interaction among members; (j) has a shared religious core (p. 23).

### *Family Social Supports*

The social support literature described the term "social support" in referring to individuals, not families. Friedman (1998c) modified the term social support to focus on the aggregate level of analysis-the family. Family social support refers to the social supports that are perceived by family members to be available/accessible to the family (the social support may or may not be used, but family members perceive that supportive persons are ready to provide aid and assistance if needed) (Friedman, 1998c, p.195). The family social support can be support from within the family, e.g. spouse, sibling; and support from outside the family, e.g. extended family or other outside systems. House (1981) structured social support as "who gives what to whom regarding which problem" (p.22). He listed four types of social support: emotional support (esteem, affection, trust, concern, listening), appraisal support (affirmation, feedback, social comparison), informational support (advice, suggestion, directives, information), and instrumental (aid in kind, money, labor, time, modifying environment). House asserted that each type of support be viewed in terms of source of support or social networks. A family's social network is the social support network that provides support to the family and refers to relatives, friends, work associates, neighbors, and community networks such as churches, health care providers, and social groups.

Social support has been studied in regard to many health and illness phenomena. There is evidence that social support has beneficial effects on a wide range of health outcomes in distressed individuals (Caplan, 1974; Cobb, 1976; Cohen & Syme, 1985; House, Karl, & Umberson, 1988). Wills (1985) reviewed the literature on social support and summarized that social support buffers the negative effects of stress on health, as well as directly influences health outcomes. Social support may initiate changes in behavior that decrease stress, facilitates recovery from a stressful event, or prevent stressful episodes from occurring (Ganster & Victor, 1988, Wills, 1985). The links between the presence of adequate social support and reduced mortality, more favorable recovery from illness, better physical/emotional health and cognitive functioning have been found in the literature (Ryan & Austin, 1989). Drawing from a wide rage of studies on the impact of social support on subsequent health, House (1981) concluded that emotional support is the most important type of support in buffering stress and facilitating health. This notion is similar to what Dunkel-Schetter (1984) found in his study of cancer patients. It was found that emotional support was mentioned as the most helpful when compared with other types of supports.

## Summary of Review of Literature

In conclusion, the review of literature shows that there are many stressors found in families with HIV/AIDS. This was found among U.S. families as well as in Africa and Thailand. The stressors are not only related to the illness, but to the daily living of families. As a result, stressors from many sources affect families facing HIV/AIDS. This study is designed to show what the challenges are that families in Thailand face when caring for someone with HIV/AIDS. Few studies have been conducted on the strengths the families have to cope with HIV/AIDS, as well as the supports they receive to help them deal with HIV/AIDS. There is a need for more studies to document the positive strengths and supports of families caring for someone with HIV/AIDS. The strengths that families use to cope with the stressors, and the supports which help family to deal with the stressors, will be examined in this study.

## Research Questions

For the purpose of this study, the research questions were:

What are the family stressors that Thai families perceive when one or more family members have HIV/AIDS?

What are the family strengths that help Thai families to cope with the stressors when one or more family members have HIV/AIDS?

What are the family social supports which help Thai families to deal with the stressors when one or more family members have HIV/AIDS?

# CHAPTER 4

# METHODS

The purpose of this study was to identify stressors, strengths, and supports of Thai families who are caring for members with HIV/AIDS. This was a descriptive study that systematically described the stressors, strengths, and supports from the family's perspective. Data were gathered from families having one or more members with a diagnosis of HIV/AIDS using an interview. There was additional anticipation that the study's findings would assist nurses in providing care to these families, and would provide the investigator with more definitive data for further research.

## Study Design

The design selected for this study was a case study design with replication. For the purpose of this study, a case study was an in-depth investigation of a family. According to Polit and Hungler (1995), case studies provide an intimate knowledge of the subject's condition, thoughts, feelings, past and present actions, intentions, and environment. This design is useful when a limited number of families are being investigated. The information obtained through this design can be useful in producing insights and hypotheses to be tested in subsequent research (Yin, 1994). The unit of analysis in this case study was the family. Data were collected from individual family members, including the person diagnosed with HIV/AIDS.

## Setting and Sample

### *Setting*

Thailand is a developing country in Southeast Asia surrounded by Burma, Laos, Cambodia, and Malaysia. It consists of four regions that cover 200,435 square miles. The total population is approximately 60 million. Sixty-five percent of the population is between 15 and 59 years old; 25% and 9% of the population are children and elderly, respectively. The population of the central region is over 20 million (Office of the Prime Minister, 2001). Bangkok, located in the central region, is the capital and the largest city with six million native residents and an unknown number of non-permanent immigrating residents. Because Bangkok and the central area are more urban and the main industrial area of the country, there are many job opportunities. This draws many immigrating workers from other poor rural regions to Bangkok.

HIV prevalence varies in different areas of Thailand. The HIV/AIDS epidemic is more advanced in the northern region, which is more rural, followed by the central region in which the city of Bangkok has the highest rate of HIV prevalence (AIDS Division, 2001b). Most research studies have been conducted in the rural northern region because of the advanced epidemic and high cooperation from people living with HIV/AIDS. HIV/AIDS is much more prevalent in northern region and is more accepted because there are many sex workers whose parents support their profession and receive monetary benefits. Little research has been done in Bangkok, because of a low level of cooperation due to the high social stigma of the disease, and a desire to hide the diagnosis.

There are a total of 115 hospitals in Bangkok: 28 public and 87 private hospitals. Twenty are specialty hospitals that provide specific health care, such as for infectious disease, mental disorders, and neurological disease. The sample for this study was derived from the public infectious disease hospital, Bamrasnaradura Hospital, located in Bangkok's greater metropolitan area, which has a specific clinic for HIV/AIDS. The rationale for using this setting was that hospital policy makers were interested in the results of the study, and hoped to utilize the findings to improve patient and family care, and a home-based care program. In addition, this hospital is one of the national HIV/AIDS treatment centers, which serves the individuals with HIV/AIDS in the central region.

### *Sample*

Ten families having a member living with HIV/AIDS participated in this study. The sample was drawn from those persons living with HIV/AIDS and their families receiving care at Bamrasnaradura Hospital. Convenience sampling was used to recruit participants who met the criteria for the study and volunteered to participate. This type of sampling was used because not all HIV/AIDS patients have disclosed their diagnosis to their families. It was essential to select patients whose diagnosis was disclosed to their families, because family members were also interviewed. For the purpose of this study, a family consisted of at least two members, an identified patient and a family member who was a primary caregiver. The researcher chose a small sample size of ten families because of the scope of this pilot study. In addition, in order to collect data from these subjects, time to build the nurse-client relationships was necessary. Both conditions restricted the size of the sample.

The patients and family members who met the following criteria were invited to participate. The inclusion criteria for HIV/AIDS patients was: (a) older than 18 years of age; (b) a minimum of six-months since the diagnosis was disclosed to the family members because it was assumed that families would be past the initial crisis of diagnosis; (c) the ability to answer orally when the questions were read; (d) no significant neurological symptoms; and (e) a physical condition that allowed the person to go to the interview room. The inclusion criteria for family members were: (a) adult family members who were identified by the subject as the members of their family, older than 18 years of age, and had the ability to answer orally when the questions were read; and (b) adolescent family members who were identified by the subject as the members of their family, were between 15-18 years of age, and had the ability to answer orally when the questions were read. In Thailand, when a person is 15-18 years old, he/she changes the title of their name and is able to legally sign a consent form, with a parent and/or guardian's permission.

## Procedure

The on-site staff nurses identified patients admitted at Bamrasnaradura Hospital. A designated nurse identified a patient who met the inclusion criteria. The nurse read a short research description to the identified patient (see Appendix L). If the patient was interested in the research, he/she was then asked if the researcher could contact him/her. After the patient's permission was obtained, the nurse contacted the researcher and gave the researcher the patient's name. Next, the patient was contacted by the researcher and invited to participate in the study. Three identified patients refused to participate. After agreeing, the patients either signed a consent form or gave oral consent. Next, they were asked to identify potential family members.

The potential family members who met the study criteria were contacted by the researcher either on the hospital units or by phone and invited to participate in the study. None of family members, who were identified by the patient, refused when the researcher contacted them. However, 13 family members were unable to participate in the interview due to a conflict schedule or a traveling problem, yet the minimum number of participants in each family consisted of a patient and a primary caregiver. Three dyads were included in the study. Those agreeing to participate and being able to give an interview became part of the sample. Recruitment continued until 10 families completed the interview.

After agreeing, the interview at the hospital was arranged. A counseling room in the hospital was used for the interview. Adult family members were asked to complete the consent form (see Appendix F, H). Adolescent family members were asked to complete the child consent form (see Appendix G, I), which included their parent/ guardian's signature.

After the consent form was obtained, the researcher reviewed the patient's chart. The researcher then assisted the family to develop their genogram. This process took approximately 40 minutes. Next, the family was asked to develop an ecomap, which took approximately 10 minutes to complete. The researcher then interviewed family members together using semi-structured interview guide. The interview was audiotape recorded with the participants' consent, and lasted approximately 40 minutes (see Figure 6). The participants were told that they had the right to discontinue the interview at any time.

*Figure 6.* Sample recruitment and procedure.

Patients admitted in Bamrasnaradura Hospital

on-site staff nurse told the patients ↓ criteria: (a) older than 18 years of age

about the research and asked for ↓ (b) the diagnosis was disclosed to family

a permission to be contacted by ↓ (c) the ability to answer orally when

the researcher ↓ the questions were read

↓ (d) no significant neurological symptoms

↓ (e) a physical condition that allowed the person

↓ to go to the interview room

Patients were invited to participate and sign consent

↓

Patients identified family members

↓

Potential family members

↓ criteria: (a) adult family members who were identified by

contacted by the researcher the family group as the members of the

through the hospital or by phone ↓ family, older than 18 years of age, and

had the ability to answer orally when the

questions were read

↓ (b) adolescent family members who were

identified by the family group as a member

of the family, were between 15-18 years of

age, and had the ability to answer orally

↓ when the questions were read

Actual sample

*Figure 6.* Sample recruitment and procedure (continued).

Actual sample

↓

The researcher invited to participate and
arranges the meeting at the hospital

↓

Actual sample came to the hospital

↓

Patient and family members went to the counseling room

↓

Family members signed the consent

↓

Researcher reviewed the patient's chart

↓

Family group developed the **genogram** together

↓

Family group developed the **ecomap** together

↓

The researcher interviewed family together using
the **semi-structured interview guide**

## Data Collection and Instruments

Demographic data were collected about each family. Additionally, data about the person's HIV/AIDS information were collected. Lastly, data were collected regarding the study variables of family stressors, family strengths, and family social supports.

The following data about the family members and the identified patients were assessed using a genogram: (a) age; (b) gender; (c) marital status; (d) education level; (e) occupation; (f) religious background; (g) health problems; (h) life events (e.g. birth, death, marriage, divorce, and illness); (i) cause of death; and (j) income level. The genogram was used to collect data on the first nine variables. Information about previous and current monthly income, which the literature indicated is important, was measured by the open-ended questions in Section I of the semi-structured interview guide.

Reviewing the patient's chart and asking questions in the semi-structured interview guide developed by the researcher collected select information about the patient's HIV/AIDS history. The HIV/AIDS information included the stage of the disease, CD4 count, route of disease transmission, opportunistic infections, times hospitalized, the time since diagnosis was established and disclosed to family, to whom the diagnosis was disclosed, family response after disclosure, past family experience with HIV/AIDS, and who was a primary caregiver.

Data about family stressors, defined as the problems, conditions, or situations that are capable of causing family instability and threaten family life, were collected using Section IV of the semi-structured interview guide developed by the researcher. Stressors which existed in daily family life as well as stressors associated with the HIV/AIDS were identified.

Data about family strengths, defined as the abilities and resources that are used by families to solve problems and cope with stressors, were collected using Section IV of the semi-structured interview guide.

Data about family social supports, defined as a process of relationship between the family and its social environment, were accomplished using the ecomap and semi-structured interview guide.

Three data collection instruments were used in this study: (a) Family Genogram, (b) Family Ecomap, and (c) a semi-structured interview guide developed by the researcher. The next section discusses each instrument and the data analysis methods. Figure 7 summarizes the study variables and the data collection instruments employed.

*Figure 7.* Variables and data collection instruments.

| Variables | Instruments | Participant(s) |
|---|---|---|
| Family stressors -HIV/AIDS associated | Semi-structure interview guide Section IV | Patient & Family |
| -non HIV/AIDS associated | Semi-structure interview guide Section IV | Patient & Family |
| Family strengths | Semi-structured interview guide Section IV | Patient & Family |
| Family social supports | Ecomap (interview) | Patient & Family |
|  | Semi-structure interview guide Section IV | Patient & Family |
| Family characteristics | Genogram (interview) | Patient & Family |
| HIV/AIDS information | Semi-structured interview guide Section III | Patient |
|  | Chart review | Patient's chart |

### *Genogram*

The genogram is “a diagram, a skeleton, a constellation showing the structure of intergenerational relationships” (Hanson, 2001b, p 179). The genogram is a family tree diagram that records information about family members and their relationships over at least three generations (McGoldrick, Gerson, & Shellenberger, 1999). The family tree indicates parents, siblings, spouses, marriage, divorces, and deaths, and provides family health information about the patient’s family. The genogram was used in this study because it allows for determination of the relationship between the family and the patient, and the connection between the family and illness. The genogram enabled the researcher to quickly gather specifically relevant information on the family and to record the information in a clear, easily readable format (McGoldrick, et al., 1999).

The genogram has undergone development since the 1970s by professionals, including nurses. The theoretical basis of the genogram is family system theory and developmental theory (McGoldrick, et al., 1999). The genogram is a visual representation of a family’s composition, structure, relationships, and other information over time. It is used as a tool to collect and present considerable and complex family data on a diagram that lends itself to interpretation/assessment based on family system theories (Sawin, Harrigan, & Woog, 1995).

There is a presentation (McGoldrick, et al., 1999), which provides detailed information on the construction of the genogram, including a basic genogram format and interpretation guideline. There has been little establishment of the psychometric properties of the genogram, and these have resulted in conflicting results. However, the continued use of genograms by several disciplines over time shows evidence of content and face validity (Sawin, et al., 1995).

Rogers and Holloway (1990) tested the genogram on 11 female patients over a 3-month period; the results showed a high degree of test-retest reliability related to structure, demographics, and life events, as well as similar rates of completion time. The results of the test for predictive validity showed that the genogram provided an average of four times as much family medical information when compared to informal interviews (Rogers & Durkin, 1984). According to cross-cultural sensitivity and variant family structures, the genogram is recognized by professionals in family therapy as being sensitive (Boyd-Franklin, 1989; McGoldrick, Pearce, & Giordano, 1982).

For the purpose of the study, the three-generation genogram was used to assess family characteristics, and to describe the families in this case study design. In this study, genogram information was obtained from all individual members. The patients and families who participated in this study developed their genograms with the researcher's assistance before proceeding to the family interview. This approach resulted in the advantage of increased reliability.

The data derived from the discussion about the genogram was used to understand the family structure, family functions, relationships, medical problems, and critical life events which may be stressing a family both currently and historically, in the systematic familial context. A narrative description of each family was used to describe the findings. In addition, the demographic data obtained from the genogram was used to describe the characteristics of the sample families (see Appendix B).

### *Ecomap*

The ecomap is "a visual representation of the family unit in relation to the community; it shows the nature of the relationships between family members and between family members and the world around them" (Hanson, 2001b, p. 181). For the purpose of this study, the ecomap was used to assess the variable of family supports. Developed with the involvement of family members, the ecomap provides an understanding of the available supports of the family (Holman, 1983). It also provides information about the strength of connections between the families, and the community. The ecomap consists of a larger circle, which refers to a family system surrounding smaller circles that refer to other systems. The genogram format of the family is placed in the larger circle. The smaller circles represent other systems such as health agencies, social institutions, extended family, friends, neighbors, and colleagues who interact with a family system. Drawing lines between the circles represents the relationships between the family and these systems. The ecomap shows the strength of the relationships by varying the texture of the lines. Different symbolic lines are used to indicate whether the relationships induce strain or give support to a family.

The investigator assisted family members in developing their ecomaps. The process of developing both the genogram and ecomap helped to build a partnership between the patient, family members, and the researcher. The data about family supports derived from the ecomap helps to understand the connections between families and their surrounding community. Qualitative data obtained from the ecomap is described in narrative language (see Appendix C).

### *Semi-structured Interview Guide*

The researcher developed a semi-structured interview guide. It was divided into four sections: (I) demographic questions; (II) HIV/AIDS information; (III) HIV/AIDS questions; and (IV) stressors, strengths, and supports questions.

*Section I.* The first section measured the relevant family demographics that were not obtained by the genogram. It contained questions requesting, family's monthly income prior to illness, family's current monthly income, and family members' employment status.

*Section II.* The second section, concerning the HIV/AIDS information, collected data from the patient's chart. The HIV/AIDS information included the stage of the disease, CD4 count, route of disease transmission, the time since diagnosis was established, opportunistic infections, and times hospitalized.

*Section III.* The third section contained open-ended questions requesting the time since diagnosis was disclosed to family, to whom the diagnosis was disclosed, the family response, former family's experience with HIV/AIDS, who had experience, and who was a primary caregiver.

*Section IV.* In this section, open-ended questions were used to ask families to identify the general stressors that existed in daily family life, specific stressors associated with HIV/AIDS, strengths that were used to cope with these stressors, and social supports that were not identified on the ecomap.

## Data Analysis

All demographic data in Section I and HIV/AIDS data in Section II of the semi-structured interview guide were categorized and summarized. Frequencies and percentiles and descriptive statistics, such as means and standard deviations, were used to describe family characteristics and HIV/AIDS information. Section III and IV of the semi-structured interview guide provided qualitative data such as problems and stressful situations, abilities and resources related to HIV/AIDS, family response to the disclosure, and past family experiences with HIV/AIDS. (see Appendix D). When the questions about stressors and strengths were asked, the check list of some possible stressors and strengths (see Figure 4, 5) was given to the participants to help them identify their stressors and strengths. The content of the audiotape-recorded interviews was transcribed and used to recall and confirm the accuracy of data.

The analysis format includes a narrative description of each family participating in the study. A family profile for each family was developed. Information obtained from the genogram, ecomap, and semi-structured interview questions was described in narrative language. The description of each family was reported according to the following format: overview of the family and its composition, patient's stage of disease, CD4 count, route of transmission, time since diagnosis was established, opportunistic infection, number of hospitalization, who and when HIV/AIDS diagnosis was disclosed to and their response, previous experience of HIV/AIDS in family, and primary caregiver.

Qualitative content analysis (Sandelowski, 2000) was used to analyze the interview data regarding family stressors, strengths, and social support. This analytic strategy was oriented toward summarizing the informational contents of the verbal data (Altheide, 1987, Morgan, 1993). Codes, which were generated from the data, were systematically applied to the data instead of using pre-existing sets of codes. Qualitative content analysis is the least interpretive of the qualitative analysis approaches in which there is no mandate to represent data in any other terms but their own. For example, the concept of stressor remains stressor and strength remains strength; they do not become a condition or consequence of some event in a theory, like in grounded theory analysis. A descriptive summary of the informational contents of data organized in a way that best fits the data is the outcome of the analysis (Sandelowski, 1998). In this study, data were organized in relation to the pre-defined concepts of interest-stressors, strengths, and social support. The researcher then coded informants' responses. These initial categories organized around family stressors, strengths, and social support were further refined over the course of analysis to best fit the data.

## Human Subjects Protection

Approval and permission was obtained from the equivalent Research Committee of the Bamrasnaradura Hospital. Letters of agreement are in Appendix K. This study was reviewed and approved by the Oregon Health & Science University Institutional Review Board for human subjects protection.

### *Risks and Benefits*

Each participant was informed of the purpose, potential risks and benefits, the rights of each participant, and the guarantee of confidentiality. Since the purpose of this study was to identify stressors, strengths, and supports of Thai families who are caring for someone with HIV/AIDS, there was no direct benefit. The possible outcome that participants had was being heard and having their experience affirmed. The risks of participating included: (a) the participants might have felt upset or experienced emotional distress as they were reminded of unpleasant past events; and (b) different answers to the questions might have caused conflict among family members. The researcher responded and stopped the interview if either situation arose. During the study, if the participants were in distress, the researcher provided referrals to appropriate hospital resources if the families needed assistance. Every participant had the right to discontinue at any time during the interview or to withdraw from the study without any effect on patient care received at the Bamrasnaradura Hospital.

### *Confidentiality*

The private conversation in the interview was audiotape recorded with the family members' permission to increase accuracy of information. To assure the confidentiality, no last names were used during taping. The recorded audiotapes were kept in a locked file and destroyed once they were transcribed with all personally identifying information deleted in the typed record. The transcripts will be kept for five years in a locked file.

Confidentiality was assured through the use of code numbers for each subject. Once the patient and family consented, they were given a code number. Only a participant's code number was recorded on the interview guide, genogram, and ecomap use in research report. There was no identifying information on any form that linked the data back to a particular patient and family. The list of participant' names and code numbers was made by the researcher to link the participants with the data forms. This list was kept in a locked file during the study and will be destroyed at the end of the 5-year period.

The consent forms were also kept in a locked file. The collected data were kept separately from the consent forms in another locked file. Only the researcher has access to all of the data. The findings were reported in anonymous and aggregated form. Neither the name, nor identity of the participants was used for publication or publicity purposes.

### *Consent*

The English consent forms were translated into the Thai language by the researcher and certified by a member of the equivalent Research Committee of the Bamrasnaradura Hospital (see Appendix J). Thai versions of the consent forms (see Appendix H) and child assent forms (see Appendix I) were used. Written consent forms were obtained from participants if they agreed to participate. Adult participants who were older than 18 years old signed the consent form. Adolescent participants who were between 15-18 years old signed the child assent form with the signature of their parent/guardian. Regardless of levels of literacy, Thai people are often unaccustomed to signing papers. In those cases, informed consent was obtained verbally from subjects and audio tape recorded after the researcher read the consent form out loud to each family member. If the subjects signed a consent form, they received a copy of the signed consent form. If the subjects gave verbal consent, they received a written copy of the consent form.

The patient's chart was reviewed with the patient's written or oral consent and a verbal consent from the PLWAs' physicians. The participants were informed that the patient's chart would be reviewed and this information was included in the consent form. In Thailand, the patient's chart belongs to the hospital. The hospital and the physicians employed by the hospital gave permission to the researcher to review the patient's chart. The researcher asked the physicians for verbal consent, but it was not necessary to obtain a written consent from the physicians in Thailand.

# CHAPTER 5

# RESULTS

The purpose of this study was to identify stressors, strengths, and supports of Thai families who are caring for family members with HIV/AIDS. The data were collected from 31 primary informants of 10 families with one or more members diagnosed with HIV/AIDS. The primary informants were interviewed using three instruments: a genogram, an ecomap, and a semi-structured interview guide. This chapter describes the findings of this study. The first section describes the characteristics of the sample families and HIV/AIDS information. The second section presents the family profile for each of the 10 families. The third section presents the analyses of data related to the research questions of family stressors, strengths, and social supports. The last section summarized the family' needs.

## Characteristics of the Sample Families and HIV/AIDS Information

The characteristics of the sample families and HIV/AIDS information were obtained through the family genogram, patient's chart review, and semi-structured family interview guide. The family genogram provided family names, number of family members, relationship of members in the family, age, gender, marital status, religion, education levels, occupations, and HIV status. The chart review contributed to the information regarding HIV/AIDS, which included stage of the disease, route of disease transmission, time since diagnosis was established, type of opportunistic infections thus far, and number of hospitalizations. The semi-structured family interviews provided household information regarding total monthly income (current and prior to the illness), members' employment status, time between diagnosis and disclosure, family's prior experience with HIV/AIDS, and identification of the primary caregiver.

A summary of the sample families is presented in the following section. Information gathered from family genograms, patients' chart reviews, and semi-structured family interviews was organized and presented as general descriptions of the families, and characteristics of the primary informants.

### *General Description of the Families*

The Thai family sample was obtained from four HIV inpatient units at Bamrasnaradura Hospital, Nonthaburi Province, Thailand. Families selected for the study had at least one adult member diagnosed with HIV/AIDS. Hospitalized members were defined as the identified patients in this study. The investigator approached identified patients and their families who met the criteria and gave permission to be contacted. Ten of thirteen potential families participated in this study. Other three families declined to participate.

After agreeing to participate in the study, ten patients were asked to identify those whom they considered family members. The patients identified a total of 34 family members, who were considered as potential participants. Of those, 21 were able to participate in the interviews. Ultimately, a total of 31 participants (ten patients and 21 family members) were the primary informants in this study.

All families were Buddhist, living in Bangkok, Bangkok's greater metropolitan area or the central region of Thailand. The family size ranged from two to seven. The data were collected from the families of two to five primary informants each. Table 1 summarizes the family size and the number of primary informants in the family. Within this sample of ten families, five (50%) were nuclear families, four (40%) were extended families and one (10%) was an unconventional family (a family of close friends who were HIV positive members of an AIDS related organization).

Prior to the illness of a family member, three families (30%) had total monthly incomes considered in a low-income range in Thailand, where they earn equal to or less than 5,000 baht monthly (equal to US $125 per month; with an exchange rate of 40 baht equal to one dollar). Seven out of ten families reported decreasing family income. At the time of the interview, seven families (70%) had total monthly incomes in a low-income range. Of these families, one family reported that they had no monthly income at the time of interview. Table 2 presents the total monthly family income. Three families (30%) reported that they did not experience income loss due to HIV/AIDS.

Two families (20%) had experienced HIV/AIDS in their families before. Both families reported that ex-partners of the identified female patients were infected with HIV and died of AIDS. Two families had more than one HIV positive members at the time of the interview; both were couples whose spouses were also HIV positive. One family was uncertain about the spouse's HIV status because she had not been tested for HIV.

Table 1.

*Family Size and Number of Primary Informants in the Family (N=10 families)*

| | Number of families | Percentage |
|---|---|---|
| Family size | | |
| 2 | 2 | 20% |
| 3 | 1 | 10% |
| 4 | 1 | 10% |
| 5 | 4 | 40% |
| 6 | 1 | 10% |
| 7 | 1 | 10% |
| Number of primary informants in the family | | |
| 2 | 3 | 30% |
| 3 | 4 | 40% |
| 4 | 2 | 20% |
| 5 | 1 | 10% |

Table 2.

*Total Monthly Family Income (N=10 families)*

| | Number of families | Percentage |
|---|---|---|
| Current total monthly family income (Thai baht) (40 baht = US $1) | | |
| Less than or equal to 5,000 baht (US $125) | 7 | 70% |
| 5,001-20,000 baht (US $125-US $500) | 0 | 0% |
| More than 20,000 baht (US $500) | 3 | 30% |
| Prior to illness total monthly family income (Thai baht) (40 baht = US $1) | | |
| Equal to or less than 5,000 baht (US $125) | 3 | 30% |
| 5,001-10,000 baht (US $125-US $250) | 2 | 20% |
| 10,001-15,000 baht (US $250-US $375) | 1 | 10% |
| 15,001-20,000 baht (US $375-US $500) | 1 | 10% |
| More than 20,000 baht (US $500) | 3 | 30% |

### *General Description of the Identified Patients*

The ages of the ten identified patients ranged from 25 to 43 years (Mean=31.3; SD=5.72). Of the 10 identified patients, six were male (60%) and four were female (40%). Forty percent of the patients had less than a high school education, 30% had high school diplomas, and 30% had college degrees. Sixty percent of the identified patients were married, 30% were single, and 10% were divorced/widowed. Prior to the illness, six identified patients (60%) were manual labor workers where as five (50%) were business clerical workers. At the time of interview, 30% of the patients were employed, 40% were unemployed, and 30% were on medical leave.

The majority of the identified patients (70%) were admitted at the time of the interview for cryptococcal meningitis; the rest (30%) were admitted for pneumocystis carrinii pneumonia. Nine identified patients (90%) became infected through heterosexual contact with partners or prostitutes, and one (10%) through homosexual contact. Eighty percent of the patients were hospitalized for the first time, the rest (20%) were hospitalized for the second time.

The identified patients were aware of their HIV status for 6 months to 5 years with a mean of 1.8 years. The average time between the diagnosis and disclosure to other family members was 10.5 months (range=0-4 years). At the time of the interview, all patients were in a symptomatic stage of HIV. They were hospitalized from opportunistic infections and were close to being discharged. Prior to this illness episode, the majority of the patients (90%) experienced one or more opportunistic infections including candidiasis, dermatosis, pulmonary tuberculosis, penicilliosis, acute/chronic diarrhea, herpes zoster/simplex, retinitis, and pneumocystis carinii pneumonia. Information pertaining to the CD4 count was not available in the patient's charts.

### *General Description of the Primary Caregivers*

The patient identified the primary caregivers as family members who were primarily responsible for providing care for the patient. Ages of the caregivers ranged from 22 to 65 years (Mean= 40; SD=14.6). Identified primary caregivers consisted of seven females (70%) and 3 males (30%). Forty percent of the caregivers were employed, 20% were unemployed, 30% temporarily quit working, and 10% were retired. The majority of them were spouses/partners (50%), followed by parents (30%). All parent-caregivers were mothers. A summary of the primary caregiver's characteristics is presented in Table 3.

### *General Description of the Primary Informants*

Beside the ten patients, 21 family members were also primary informants in this study. They consisted of nine males (43%) and twelve females (57%). All of them were adults between 21 and 65 years old, with the exception of one member who was a 15-year-old adolescent. These primary informants included spouses (28.6%), parents (28.6%), children (9.5%), siblings (23.8%), and friends (9.5%). A summary of the characteristics of the primary informants is presented in Table 4.

Table 3

*Characteristics of the Primary Caregivers (N=10 primary caregivers)*

| | Number of primary caregivers | Percentage |
|---|---|---|
| Gender | | |
| Male | 3 | 30% |
| Female | 7 | 70% |
| Employment status | | |
| Employed | 4 | 40% |
| Unemployed | 2 | 20% |
| Temporarily quit working | 3 | 30% |
| Retired | 1 | 10% |
| Caregiver's relationship with the patient | | |
| Spouse/partner | 5 | 50% |
| Parents | 3 | 30% |
| Sibling | 1 | 10% |
| Friend | 1 | 10% |

Table 4

*Characteristics of the Primary Informants (N=21 primary informants)*

| | Number of primary informants | Percentage |
|---|---|---|
| Gender | | |
| Male | 9 | 43.0% |
| Female | 12 | 57.0% |
| Primary informant's relationship with the identified patient | | |
| Parent | 6 | 28.6% |
| Spouse/partner | 6 | 28.6% |
| Children | 2 | 9.5% |
| Sibling | 5 | 23.8% |
| Friend | 2 | 9.5% |

## Family Profile: Description of Each Family

The case studies are presented in the form of family profiles. The family profiles were obtained from the data gathered by chart review, genogram, ecomap, and semi-structured interview guide. The description of each family begins with the interview data which provides an overview of the family with respect to family type, composition, residential location/ arrangement, and who participated in the study. Then, the characteristics of the identified patients and family members such as age, occupation, education, and religion were presented as well as family monthly income. Next, the data collected from the patient's chart review is summarized. The information included time since diagnosis was established, reason of having HIV test, route of transmission, who else was infected, stage of the disease, previous opportunistic infections, number and cause of hospitalizations. Lastly, the findings obtained from the interview questions are presented. The questions included the following:

a) Who is your primary caregiver?
b) When were the family members told about the HIV/AIDS diagnosis?
c) Who did you tell? How did they respond?
d) Has your family had any experience with HIV/AIDS before? Who had an experience with HIV/AIDS before?

For reasons of confidentiality, family's names are replaced by different letters. In order to be able to identify each member in the family, the family relationships are described from the patient's point of view. For example, the brother of the patient's wife is called the patient's brother in-law.

The next section presents each case study. A family profile contains the description of the family. The family's genogram and ecomap are contained in Appendix A.

### *Family A*

Family A was an extended family in which five persons lived in the household (see Appendix A). The family lived in the suburban area of the central region. This family consisted of two couples and one child. The first couple consisted of the identified patient and his wife. The second couple was the patient's brother in-law, his pregnant wife, and their 3-year-old child. The second couple had a business and owned a small steel factory. The identified patient and his wife had lived with the brother's family since they were married a year ago. Despite living in the same household, the two couples had separate financial affairs. Four adult family members participated in the study.

The identified patient was a 27-year-old male. He worked as a full-time employee of his brother in-law's small steel factory. The patient's wife was a 28-year-old female and worked full-time as a seamstress. Their educational background was primary school level. Their religion was Buddhist. The family monthly income decreased from 9,000 baht (US $225) to 4,000 baht (US $100) because the identified patient could not work due to the illness.

The identified patient had been diagnosed with HIV/AIDS for seven months at the time of the interview. The patient had a HIV test after his wife, who was three months pregnant, found out that she was HIV positive at the prenatal clinic. Heterosexual relations with prostitutes prior to marriage were the cause of infection in the identified patient. The disease was transmitted to his wife. The identified patient was in a symptomatic stage of AIDS illness. Since diagnosis, he had several opportunistic infections including herpes simplex and candidiasis. The cause of this first hospitalization at the time of the interview was pneumocystis carinii pneumonia. The patient's wife was identified as the primary caregiver. She herself was HIV positive, but asymptomatic. She terminated her three-month-pregnancy seven months ago, as advised by her health care provider.

The patient's wife, brother in-law, sister in-law, and mother were told about the couple's HIV status immediately after the diagnosis. All felt sorry for the couple, and were supportive, encouraging, and sympathetic. The diagnosis was not disclosed to the wife's parents because of possible discrimination. The family did not have a prior experience with HIV/AIDS.

### *Family B*

Family B was a nuclear family, which consisted of the husband and wife who were the same age of 38 (see Appendix A). Both participated in the study. The family rented a room in a large house located in the Bangkok metropolitan area. They had been married for 3 years with no children. The wife, who was the identified patient, was a laundress. The husband worked with a small contractor who built steel doors. The couple had a primary education and their religion was Buddhist. The family income prior to this illness episode was 17,000 baht (US $425) per month. The couple did not have any savings. They lost their income since the identified patient was sick and unable to do laundry seven months ago. Since then, the husband earned little income because he often missed work to take care of his wife. At the time of the interview, the family earned approximately 1,000 baht (US $25) a month.

The identified patient had been diagnosed HIV positive for seven months at the time of interview. She was tested at a small clinic when she experienced severe weight loss and an unknown fever. Later her husband was tested and it was found that he was HIV positive as well. The identified patient contracted HIV from her husband. The husband became infected through heterosexual contact with prostitutes before and after marriage. So far he had been healthy, but occasionally had skin infections, an HIV related symptom. The identified patient was in a symptomatic stage of HIV. Since diagnosis, she had pulmonary tuberculosis and chronic diarrhea. At the time of interview, she was hospitalized for the first time with cryptococcal meningitis. The patient's husband was identified as the primary caregiver.

Only two people, the husband's mother and their landlord with whom they lived and was very close to knew about their diagnoses. The husband's mother sympathized with the couple, but could only give emotional support because she was poor and lived far away. The landlord understood their situation and gave some financial help. The identified patient's mother and sisters were not told about the HIV diagnosis because she was afraid that they would discriminate against her and her husband. They said that the identified patient had a viral infection in her brain. The identified patient's mother and siblings expressed their concerns about the patient's condition and gave encouragement. The family did not have any prior experience with HIV/AIDS.

### *Family C*

Family C was a nuclear family consisting of a 32-year-old husband and 29-year-old wife (see Appendix A). Both participated in the study. The wife was the identified patient who was diagnosed with HIV eight months ago. The couple rented a home/business building in a province adjacent to Bangkok. Their religion was Buddhist. They had been married for two years and had high school educations. The couple had a small business in audio system manufacturing where the husband was a manager and the identified patient was his assistant. The family income decreased from 40,000 baht (US $1,000) to 5,000 baht (US $125) a month since the identified patient became ill a few months ago. The illness of the identified patient forced the family to cut back their time running the business. The husband assumed the primary caregiver role, while cutting his work to half time or less. Her ex-husband, who became ill and died from AIDS after they separated, infected the identified patient. After the ex-husband's death, the identified patient had a check up at a clinic and requested a HIV test. A month after she found out that she was HIV positive, she disclosed her HIV status to her current husband, father and siblings. The husband's HIV test was negative at the time of interview. The identified patient was in symptomatic stage of HIV. She was admitted to a local hospital for a severe headache. At the time of interview, her second hospitalization was to treat cryptococcal meningitis.

The diagnosis was not disclosed to the husband's family because they had superficial knowledge about AIDS and would possibly discriminate against the identified patient. To protect their business, the employees were not told her about HIV status. The identified patient's family members were supportive and offered to have her stay with them in her hometown when she needed hospice care. The husband's first reaction to the disclosure was anger at his wife for lying that her ex-husband had died of cancer and worried about transmission to him. After he found out that he was HIV negative, he felt sorry for his wife, forgave her, and offered to take care of her.

### *Family D*

Family D is a nuclear family consisting of a 30-year-old husband and 30-year-old wife (see Appendix A). Both participated in the study. The couple was married for a year and had no children. They lived in an apartment in Bangkok. The husband, the identified patient, was a sales person in a travel company. His wife owned a small leather booth in a mall. Both were Buddhist and had completed high school. The family's monthly income decreased from 10,000 baht (US $250) to 3,000 baht (US $75) after the wife became the primary caregiver and sold her business to a friend.

The identified patient was in symptomatic stage of HIV. He had been diagnosed with HIV for 10 months. He was given the HIV test because of unknown headache and fatigue. HIV disease was transmitted through heterosexual relationships with prostitutes prior the marriage. The wife was HIV negative. At the time of interview, the identified patient was in the symptomatic stage of HIV and had been on sick leave. Since his diagnosis, he had chronic diarrhea as well as candidiasis. He was hospitalized for the first time with pneumocystis carinii pneumonia. The wife assumed the responsibility of caregiver.

The wife, the couple's mothers, and a few close friends were told about the HIV/AIDS diagnosis four months after the diagnosis, when his health significantly deteriorated. The identified patient did not experience any discrimination or rejection by them. However, the diagnosis was not disclosed to the identified patient's co-workers because of the threat to his job. The wife was forgiving and provided care for her husband. She was a determined caregiver and advocated for other caregivers in the hospital. The family did not have any prior experience with HIV/AIDS.

### *Family E*

Family E was a single parent family of four consisting of a 60-year-old mother, two daughters, and a 29-year-old son who was the identified patient (see Appendix A). The family lived in their own home in suburban area outside Bangkok. Four members lived in the household, but only the mother, younger sister, and the identified patient participated in the study. The identified patient was a single man who ran a family-owned laundry business. He had an associate's degree in electronics. The mother was a retired hairdresser and had a small salon. The family's religion was Buddhist. The family income decreased from 4,000 baht (US $100) to 3,000 baht ($75) per month because the mother closed her salon and became the primary caregiver of her son.

The route of transmission was uncertain. The identified patient suspected that he had been infected from visiting prostitutes when he was in college. He tested HIV positive while receiving treatment at a STD clinic five years ago. He was working in a cloth factory when he was diagnosed. He resigned because he was afraid that his employer would find out about his HIV status. Before he entered the symptomatic stage, he became a Buddhist monk for two years to help cope with living with HIV and prepare for his impending death. He has been using herbal medicine to cure AIDS while he was asymptomatic.

Since last year, he had pulmonary TB, candidiasis, and a skin infection. He was admitted to the hospital for the first time with cryptococcal meningitis at the time of interview. The mother and younger sister were told about the diagnosis when he was sick with TB four years after being diagnosed HIV positive. They were sad, but very supportive and encouraging. The diagnosis was not disclosed to his older sister who ran the laundry business for him, because he wanted to protect her from sadness about his impeding death. The identified patient's aunt who had raised him and to whom he was very close was not told about his diagnosis because she was very fragile and her health status was not good. The family had no previous experience with HIV/AIDS.

### *Family F*

Family F is an extended family of seven individuals in which six lived in the household (see Appendix A). They resided in two separated sections in the same house located in a small province in the central region. The family consisted of the identified patient, a 43-year-old single mother, her three children, her brother, her sister in law and niece. The identified patient's brother, a lawyer, and sister-in-law, a housewife, owned the house they lived in. They lived in another section of the house with their 10-year-old daughter. The identified patient lived alone in another section of the house. Her 15-year-old son and 12-year-old daughter stayed with her brother in the other part of the house. Her 21-year-old son lives in another town. The 15-year-old son dropped out of high school last year and was unemployed at the time. The family's religion was Buddhist. The identified patient, her brother, sister-in-law, 21-year-old son, and 15-year-old son participated in the study. The identified patient had primary school education and owned a small convenience store, which was located in the front part of her place. The store was closed when she became ill six months ago. The identified patient's income, which came from her grocery and loan business decreased from 5,000 baht (US $125) to 3,000 (US $75) baht per month after the store was closed.

While living with her husband four years ago, the identified patient had herpes zoster. She went to get treatment and tested HIV positive. Her husband, who later tested HIV positive, passed on the disease to her. He had been visiting prostitutes after they had been married. One month after the diagnosis, the identified patient told her children and her brother that she was HIV positive and divorced her husband. She moved in with her brother to escape neighbors' suspiciousness about the disease. Her husband died of AIDS three years ago. All her children were HIV negative. The opportunistic infections since diagnosis included herpes zoster, pulmonary TB, retinitis, and candidiasis. At the time of the interview, she was treated for cryptococcal meningitis and hospitalized for the first time. Her brother is the primary caregiver with her 15-year-old son is a secondary caregiver.

The identified patient was symptomatic, but able to take care of herself while isolated herself from the rest of family members because of fear of HIV transmission to them. Her children and brother's family were told about the diagnosis. They were encouraging and did not have negative responses toward the identified patient. The HIV status was disclosed to her siblings, but they felt disgusted and distanced themselves from her. Thus, the identified patient decided not to disclose her diagnosis to anyone else. The identified patient felt that she was a burden to her family, but they gave her encouragement to live and maintained hope that she would be alive for a long time. Her brother made sure that she received appropriate treatment to be cured from the illness. The identified patient did not leave the house to avoid suspicious neighbors and others because of her typical AIDS appearance.

### *Family G*

Family G was a nuclear family of four who lived in Bangkok metropolitan area (see Appendix A). This family consisted of elder parents, 31-year-old son (the identified patient) and 27-year-old daughter. The identified patient was single, a navy employee with a college education. His 58-year-old father also worked in the navy whereas a 54-year-old mother was a housewife. The younger sister was an insurance sales-person. The parents lived in their own home. Their religion was Buddhist. The identified patient, his father, and mother participated in the study. Prior to the HIV diagnosis, the identified patient had lived with his girlfriend for a year in her apartment without his parents' acknowledgment. He moved back home with his parents after he was symptomatic and ill. The family income of 20,000 baht (US $500) did not change after the identified patient became ill because he still had his job in navy. However, the identified patient was planning to quit his job when his health significantly deteriorated to keep his HIV/AIDS diagnosis secret from his employers. He would lose his health insurance if he quit his job. He was on sick leave at the time of the interview.

The identified patient had been diagnosed with HIV/AIDS for eight months at the time of interview. He had AIDS related symptoms including fever, and weight lost. His mother was worried and told him to have a HIV test. He told his parents and girlfriend that he was HIV positive after he found out that he was HIV positive. He believed that he contracted HIV from visiting prostitutes before he met his girlfriend. His girlfriend did not have negative feelings toward him. Although they separated, she frequently visited him at his parent's house. She was healthy and refused to be tested for HIV. The identified patient's sister was not told about the diagnosis because the parents were afraid that she would be scared of the disease transmission. His mother is the primary caregiver.

The identified patient was in the symptomatic stage of HIV and he frequently had oral candidiasis. The cause of the first hospitalization at the time of the study was cryptococcal meningitis. The identified patient was referred to the hospital because there was no bed available at another hospital where the patient had been diagnosed and received treatment. His doctor planned to refer him back to the other hospital as soon as possible.

His mother was his primary caregiver whereas his father was a secondary caregiver. The mother herself was not healthy. She had hand surgery the year before. The parents who were very religious and often attended church had mixed feeling about their AIDS afflicted son. They were angry that their son ignored the family's taboo about visiting prostitutes and having premarital sexual relations (with girlfriend). They considered that he had sinned and his "karma" led to his HIV affliction. They were disappointed with his behaviors that led him to a premature death. At the same time, they sympathized with their young son regarding the suffering and pain he had experienced. The identified patient blamed himself for causing trouble for his family. Nobody besides his parents and girlfriend were told about his HIV status. The family tried to keep it from the navy co-workers, because the stigma attached to AIDS would jeopardize the identified patient and his father's careers in the navy. His colleagues were already suspicious about his AIDS typical appearances and hospitalization. The family did not have prior experience with HIV/AIDS.

### *Family H*

Family H was an extended family consisting of elder parents, four daughters and a son-in-law (see Appendix A). The 25-year-old identified patient was the youngest daughter of four children. She had been married for 5 years to a man one year older than herself and they had no children together. Both had high school education. The parents were in their 60s and retired. The parents owned a fireworks factory. The identified patient and her husband worked in the factory as well as her siblings. The couple lived with the patient's parents and three other siblings. The family lived in a province adjacent to Bangkok where the house and fireworks factory were in the same location. The family's religion was Buddhist. The family monthly income of 30,000 baht (US $750) did not change. The identified patient, her husband, and her mother participated in the study.

The identified patient's HIV exposure resulted from a premarital relationship with her ex-boyfriend. She was diagnosed HIV positive four and a half years ago. She had the HIV test because she suspected that her ex-boyfriend had AIDS. The diagnosis was not disclosed to her husband and family until she started having AIDS related symptoms six months ago. Her current husband had tested HIV negative. Prior to the first hospitalization, the identified patient was asymptomatic and had no opportunistic infection. At the time of the interview, she was in a symptomatic stage of HIV and was treated for pneumocystis carinii pneumonia. She was hospitalized for the first time. Her mother assumed the role of primary caregiver at home as well as at the hospital to allow her husband to continue to work full time.

The patient's husband was angry and wanted a divorce at first, but later decided to stay with her after he found out that he was HIV negative. He forgave her and had sympathy because she was naive and very young at that time. The couple used condoms for birth control while living together. Other family members did not have negative responses, and were very supportive to the couple. The family did not have prior experience with HIV/AIDS before.

### *Family I*

Family I is an extended family, which included a 35-year-old husband (identified patient), 32-year-old wife, 66-year-old mother, and two older brothers (see Appendix A). The family was originally from the northern region. The family's religion was Buddhist. The identified patient and his wife moved to Bangkok to work in a government institution in Bangkok. Recently, his mother moved in with the couple. She had diabetes and was receiving treatment from the hospital. The couple had been married for two years and had no children. Both had college education. The patient and his wife participated in the study. The family monthly income was 20,000 baht (US $500) before and after diagnosis. The identified patient had health insurance through his work.

The identified patient was diagnosed with HIV six months prior when he donated blood to the Red Cross. He believed that he contracted HIV through sexual relationships with either ex-girlfriends or prostitutes before he was married. His wife was told about his HIV status two weeks after the diagnosis. The identified patient's wife had not been tested for HIV, but she was healthy. She refused to be tested for HIV because she thought that it was no use. Her first reaction to the disclosure of her husband's HIV status was shock, anger, sadness, fear of rejection from others, and fear of death. At the time of interview, she was very depressed and on anti-depressant medication. She was very worried about her husband's rapid deteriorating health and lost hope for him getting better. The identified patient's wife was the primary caregiver.

The identified patient was symptomatic and not doing well, he had missed work a lot since the diagnosis. His first hospitalization was to treat pneumonia. At the time of interview, he was hospitalized because of cryptococcal meningitis. He was running out of sick leave and was thinking about resigning from his job before he was too sick and his colleagues knew he had AIDS. The identified patient revealed the diagnosis to his wife, but not to his brothers because he was afraid that they would feel disgusted and would reject he and his wife. His mother also was not told about his diagnosis because of her poor health. The identified patient planned to tell others that he had brain cancer. Nobody in the family had prior experience with HIV/AIDS.

### *Family J*

Family J had an atypical family structure in which the family consisted of three members who were close friends (see Appendix A). The identified patient was a 26-year-old former gay prostitute. He had a primary education and was Buddhist. The two females were his friends who he had met and lived with at the AIDS related organization eight months prior to the interview. All were HIV positive. The identified patient was cut off from his family when he was young and he felt that these two friends were significant to him as family members. The first woman was a 29-year-old former salesperson. The second woman was a 28-year-old former prostitute. Both now worked as temporary staff of the AIDS related organization where they lived. The identified patient had no monthly income. He was assisted by the organization in housing, food, medical treatment and other expenses. The identified patient and his two friends participated in the study.

The identified patient grew up in a small farming town of the rural northeastern region with seven siblings in the poor family. He ran away from home to Bangkok when he was 16 years old and never went back home or kept in touch with anyone in his family. He rented an apartment with his gay friends, and made a living by being a prostitute in a public park for 10 years. He heard about AIDS on television and suspected that he might have it because he had the typical symptoms of AIDS such as fatigue, fever, skin lesions, and weight lost. Ten months prior to the interview, he went to a clinic for treatment of diarrhea and tested positive for HIV.

HIV was contracted through homosexual relations with his clients. The doctor told him to stop his prostitution in order to prevent re-infection and passing on the disease to others. He continued working as a way to kill himself by getting more viruses and for revenge. Two months after his diagnosis, he met a staff member from a non-profit AIDS related organization and received help from the organization. He moved out of the apartment to the organization's building, where they accommodated several people living with HIV who were neglected by their families. He helped with some minor work for the organization, as much as he could, in return for housing and food. The 28-year-old friend was the primary caregiver and the 29-year-old friend was the secondary caregiver. Although they were both also HIV positive, they were healthy. The patient was very grateful for his two friends who had taken care of him physically and emotionally since he had moved in with them.

The identified patient was in a symptomatic stage of HIV. Since diagnosis, he had acute and chronic diarrhea and skin infections. He was hospitalized for the first time with cryptococcal meningitis. The identified patient did not contact his family. He experienced guilt and shame from running away from home, being a gay prostitute, and living with HIV/AIDS. He considered his life too sinful and worthless to try and go back and have his family take care of him. However, he had been thinking about going back to die at home surrounded by his family, but he was not certain that his parents would accept him. He believed they would be ashamed of him being gay and infected by AIDS. He felt very lonely, isolated, and depressed. He had no hope to live and wished to die soon to end his feelings of pain and shame. His major fear was a lonely, painful, and unpleasant death at the end his life which he anticipated to come very soon.

## Family Stressors, Strengths and Social Supports

Reported in the following sections is a summary of findings across all families regarding the family stressors, strengths, and social support in Thai families caring for a person living with HIV/AIDS. The data came from semi-structured interviews, which were one to one and a half hours long. Each identified patients and family members who consented to participate were interviewed together by the researcher. Data are presented relating to the study's research questions.

### *Family Stressors*

To answer the research question, "What are the family stressors that Thai families perceive when one or more family members have HIV/AIDS?" family members were asked two questions: (a) what are the problems and stressful situations associated with HIV/AIDS which you have experienced, and (b) what are the problems and stressful situations in your daily life which are not related to HIV/AIDS? The findings are organized into two parts. The first part displays the family stressors that are associated with HIV/AIDS. The second part describes the family stressors that are not associated with HIV/AIDS.

### *HIV/AIDS Associated Stressors*

In this study, all families caring for a family member living with HIV/AIDS were able to describe more than one family stressor that was associated with HIV/AIDS. Nine categories of family stressors related to HIV/AIDS emerged from the analysis. The following sections present the stressors that were listed from the most to the least burdensome according to the families' perceptions. They included financial burden, discrimination and rejection, concealing the HIV/AIDS diagnosis, caregiving tasks, caregiver's burnout, PLWA's uncertain health status, PLWA's emotional suffering, struggling with the health care system, and planning for impending death. Most family stressors were identified based on a perspective of the whole family; however, some family stressors were specific to a particular family member's perception (i.e., PLWA, caregiver). Caregiving tasks, caregiver's burnout, and struggling with the health care system were related to the caregivers' perception, whereas PLWA's emotional suffering emerged from the perspective of the PLWAs.

*Financial burden.* The majority of families mentioned financial burden as their major concern. There were two sub themes regarding financial burden: (a) leading factors for financial burden, and (b) strategies to maintain financial status.

It was found that four factors led to a family's financial burden. They included: (a) cost of HIV/AIDS medical care, (b) loss of family income, (c) cost of transportation to health care facilities, and (d) caregiving related expenses.

Cost of HIV/AIDS medical care were high because it is a chronic disease and requires expensive medications to treat the opportunistic infections. The cost of medical care included medications, laboratory tests, investigative procedures, hospitalization, and transportation. All families mentioned the high cost of HIV/AIDS medical care. Few families in this study had secure financial resources, thus they could afford the cost of HIV/AIDS medical care without having financial strain. However, most families experienced financial strain when they faced expensive medical care bills, especially medication bills. A thirty-year-old wife described her situation:

> His medication is very expensive--it affects us a lot. Usually, we paid about 3,000-4,000 baht per month for his medication for his normal clinic visits. When he was admitted into the hospital, we paid more. So far, for this hospital stay, we paid 30,000 baht already for his drugs only.

Besides the high cost of HIV/AIDS treatments and care, loss of family income added to their financial burden. Several families experienced decreasing family income because the PLWAs were sick and no longer were able to work or operate their business, particularly when the PLWA was the head of the household. Some families encountered a heavier financial strain when a family member assumed a caregiver role. Loss of one or more wage earners affected the family income. For example, some caregivers, who were also wage earners of the family, reported that they struggled financially because they were missing work or had quit their job/business due to a the demanding care of the PLWAs. A wife caregiver of a husband, who was a salesman, was unable to run her business since her husband needed attention and care.

> We live on his salary because I currently have no income. I sold my shoe business to my sister, because I don't have time to run it any more. My husband's care consumes all my time and energy.

A husband caregiver, who built stereos for a living, explained that he reduced his business and thus income because he was providing care for his wife.

> I don't earn as much money as I used to. I cut down my business about half to be able to take care of her–taking her to the bathroom, giving her medication, taking her to see the doctor. While she is in the hospital, I close my office to be with her.

One family had no income at the time of interview. A husband caregiver recounted his strategy to survive without an income, while taking care of his wife is in the hospital.

> We have no income because my wife hasn't worked for several months now and I haven't worked for two weeks since she is in the hospital. Some days, I don't even have money for a bus fare to the hospital. Because I get paid on a daily basis, I go back to work for a day to earn some money, so I can come to the hospital the next day.

Missing work to take care of a PLWA can be a threat to a caregiver's employment, which will lead to increasing financial insecurity. A wife caregiver expressed her concerns about losing her factory job while caring for her husband in the hospital for three weeks.

> I am using up all my days off. I have to go back to work soon, otherwise my boss will fire me. I don't want him lying in bed alone, but we need money too.

Transporting the PLWAs to and from health care facilities was a major expense for some families. Frequent doctor visits and emergency care visits were common for a terminally ill family member. Several families lived at a distance from the health care facility and did not own a car. Most PLWAs were too sick to take public transportation. The cost of renting a car or taxi to take a patient to a clinic or hospital can become expensive. One family experienced high cost of transportation because of the PLWA's unstable condition, which caused them to travel back and forth between the health care facility and home.

> This time, we rented our neighbor's car to take him here. He was in the observation room for one night and was given IV fluid, and then the doctor sent him home the next day. A day after he got back, his condition was getting worse, so we had to bring him in again. It costs a lot taking him in and out of the hospital.

Besides the family's daily living expenses at home, there was caregiving related expense. Caregiving related expenses included the cost of food and nutritional supplements for PLWAs, caregivers' personal expenses, as well as caregiving supplies.

The families believed that nutritious food would help the PLWAs fight the disease, maintain health status, and prolong life. It is thought that PLWAs should eat specific foods that help the body heal, and not eat particular foods that make the disease get worse. Therefore, families focused on what the PLWAs were eating, and fed them nutritious food, vitamins, and food supplements. For example, one family explained that they spent money on vitamins and food supplements. Others told them that it would nurture health and prolong life of their love one. A mother caregiver said that her son needed extra food because he could not eat hospital food.

> He needs good nutritious food when he is sick and the hospital's food doesn't taste good. I have to bring his favorite food every day to increase his appetite.

While PLWAs were in the hospital, caregivers were not allowed to stay at the hospital at night. They commuted to take care of the PLWAs at the hospital everyday. The caregivers' personal expenses included their transportation to health care facilities, meals, and sometime accommodations if the PLWAs were in critical condition. A 60-year-old mother, who was a primary caregiver of her son, illustrates this situation:

> I need money to spend when I come here to visit him—either from my daughter or borrowing from my friend. That is not only for his medication bill if there is any that day, but for my bus fare, my meals. Some day I buy some things for him to use in the hospital.

In addition, families needed proper caregiving supplies to provide care to the PLWAs at home. PLWA's supplies such as masks, gloves, pampers, bedpans, washcloths, disinfectant detergent, caring utensils, etc. were mentioned as additional expenses for the families.

> I bought him a bedpan and a urine container like what they use in the hospital. So he doesn't have to go to the rest room downstairs. It is an additional expense that you pay to make thing works at home.

Another sub-themes regarding financial burden is the strategies to maintain financial status. Financial strain forced the families to seek all possible financial resources to obtain money to pay for medical, caregiving, transportation, and other living expenses. Few PLWAs had health insurance through their employers, but most did not. Therefore, families had to be responsible for the cost of medical care and caregiving expenses. Families mentioned that finding financial resources to cover the expenses was also stressful. Some strategies that families employed were using savings, selling material goods, borrowing money, and seeking social welfare.

A husband, whose wife was hospitalized two times since she was diagnosed with HIV/AIDS, revealed that he spent most of the family's savings on payment for her care. This was money that they had saved for a new house.

> Before she came here (the hospital), she stayed in the private hospital. Her hospital bills were very expensive. We had to use money we saved for a new house to pay the hospital. This time we decided to go to a public hospital. It is cheaper here.

Some families revealed that they sold their material goods such as a car or jewels in order to cover expenses. One family discussed their financial problem and how they cope with the situation.

> At this hospital, we got a medication bill every few days. At first, we used our savings. After a while, the money was gone, but she isn't any better and the bills keep coming. Our relatives and friends already gave us money. I can't go to them anymore. So, I sold my own car to get some money. I have to take a bus to see my wife.

Another family discussed how the family used their material resources to secure their financial situation.

> Right now, our expenses are more than our income. I don't know what to do. So, I sold everything—my gold necklaces, my wedding ring, his motorcycle. Anything that I can sell to help him get good treatment, so he is cured and can go home.

At the early phase of the illness, most families attempted to pay their medical expenses using their own resources. However, as the disease progressed with more expenses, the families began borrowing money from other family members, relatives, friends, and loaners. For some families, after a long course of illness and multiple doctor visits, the families fell into unavoidable debt. A husband talked about his growing debts and his use of borrowing money as a strategy.

> Our income is decreasing, but our expenses are increasing. Our family and relatives are unable to help us anymore. They are not wealthy or anything. So, I took several small loans from my boss and loaners.

As the PLWAs' illness progressed to the terminal stage in which complex and intensive care was required, the families exhausted their financial resources; they began using social welfare, for which they become eligible. The families used social welfare as the last resort when they no longer could pay the medical expenses themselves. A wife described her situation and her sense of guilt while obtaining the social welfare.

> I know that there are others who are poorer than us. I don't want to use social welfare, if I don't have to. My husband has been sick for a while, our money was gone paying for his treatments. I have paid all my bills except the last one. I told the staff that I can't pay this bill, but she thinks that I don't want to pay. I explained to her that I have some money that his brother gave me, but if I spend that on medication, I won't have any left for other expenses. I got the social welfare to help with that bill, but that was intimidating and I felt bad that I had to take it.

In summary, financial burden causes stressful situations to the families. Loss of family income, cost of HIV/AIDS medical care, cost of transportation, and caregiving related expenses contributed to the family's financial burden. It is evident that providing care to PLWAs decreased the family's financial security and prosperity. They used strategies including using savings, selling material goods, borrowing money, and seeking social welfare to pay for expenses.

*Discrimination and rejection.* Discrimination and rejection from others was another family stressor that emerged from the analysis. Four sub-themes relating to discrimination and rejection included: (a) leading factors of discrimination and rejection, (b) actual experiences of discrimination and rejection, (c) anticipation of discrimination and rejection, and (d) strategies to prevent or avoid discrimination and rejection.

Four factors leading to discrimination and rejection were identified: (a) social stigma due to the negative public campaign, (b) physical appearance of AIDS, (c) superficial or inaccurate knowledge about HIV/AIDS, and (d) unacceptable behaviors associated with HIV/AIDS.

The first factor leading to discrimination and rejection is the social stigma due to the negative public campaign. HIV/AIDS is a highly stigmatized disease. AIDS-related stigma persists in Thai society because of the widespread negative image of HIV/AIDS promoted by the early first public media campaign on AIDS. A PLWA said:

> Most people feel disgusted by people who have AIDS, because TV, newspapers, and posters present scary pictures of people who are dying from AIDS. The AIDS campaign says negative things about the disease and sends a message that AIDS is scary and disgusting. That campaign makes people scare and discriminate against me.

Physical appearance of AIDS is another factor leading to discrimination and rejection. The common physical appearances of a PLWA (emaciation, and pale skin with dark lesions) engendered feelings of disgust, and fear of being contaminated, which lead to discrimination and rejection of the PLWA. Employed PLWAs in this study anticipated that their co-workers would reject them when their AIDS physical appearance was obvious. In some instances, unsightly manifestations, if not the health condition, would force the PLWAs to resign from their jobs to avoid discrimination and rejection at work.

The third factor, which leads to discrimination and rejection, is superficial or inaccurate knowledge about HIV/AIDS. The families mentioned that people who had superficial or inaccurate knowledge of HIV/AIDS were more likely to discriminate and reject them. Inaccurate understanding about HIV/AIDS transmission created unreasonable fear of contagion that, in one case, interfered with the willingness of the family of origin to accept or care for their love one. The following narrative illustrates that circumstance.

> ...I will die here alone. I decided that I wouldn't go back to my hometown--to my mother. I can't tell my mother that I have AIDS. People don't know how this disease is transmitted and that one could care for an infected person without contracting the disease.

The last factor involves unacceptable behaviors associated with HIV/AIDS. Thai Society devalues people who have deviant behaviors such as homosexual relations, injection drug use, and visiting prostitutes. Stigmatization of these behaviors leads to social discrimination against PLWAs. A homosexual PLWA's view provided an example of how he believed and perceived a person who contracted HIV by being deviant.

> ...I am gay and was selling sex. People see me as a bad and dirty person. They don't sympathize me or socialize with me. They might think I deserve to die of AIDS.

Promiscuity was associated with HIV infection of the male PLWAs. A mother, whose 29-year-old single son contracted HIV from visiting prostitutes, described her perception of AIDS victims as being condemned as promiscuous, and brought the deadly disease on themselves by visiting prostitutes.

> People always think that an infected person must play around and be promiscuous. If they were not promiscuous, they would not die from AIDS. It (AIDS) is not like...it can happen to you naturally like cancer. That person (an infected person) must have done a bad thing to get it.

Actual experience of discrimination and rejection is the second sub-theme relating to discrimination and rejection. Some PLWAs and family members reported that they had direct experience with discrimination and rejection from others including their family members, friends, relatives, neighbors, health care providers as well as strangers. A 43-year-old PLWA described her direct experience of discrimination and rejection from some of her own family members.

> I think my sisters are scared of me. They stopped contacting me and visiting me. They completely ignored me after they knew from my brother that I have AIDS.

A 29-year-old PLWA recapped his feeling of alienation while he was out in public.

> My body is showing that I am an infected person. Everywhere, I feel like an alien because people stare at me and they keep a distance or walk away from me.

Family members also experienced discrimination and rejection. For example, a 15-year-old son of a PLWA reported that a neighborhood store refused to sell goods to him, and his friends stopped being friends with him because they thought that his mother had AIDS.

In some health care facilities, discrimination from health care providers exists. A husband of a PLWA described his experience of this unwillingness and ignorance from health care providers.

> At the previous hospital she was in, I felt like the doctor was not willing to treat her (the HIV positive wife). He tried to convince me to take her here, but I insisted that she stayed there. When she was there, the nurses didn't come to check on her the whole night. In the morning, they waited for me to come and give her a bath. As I remember, they didn't even get close to her.

Anticipation of discrimination and rejection is another sub-themes relating to discrimination and rejection. Some families learn from their previous experience of seeing or hearing other PLWAs and families being discriminated or rejected. Therefore, they anticipated the same reactions for themselves. A HIV negative husband of a wife living with HIV/AIDS anticipated his parents' reaction to people who contracted HIV.

> My parents live in northeastern rural area. They know little about AIDS and that it (AIDS) doesn't transmit easily. Like most people, they will be very afraid of contamination from everything that an infected person touches or uses--not to mention living in the same house with her (the wife)

Another example of anticipated discrimination is evidenced in the work place.

> He (the father) and I work at the same place (in the navy). It will be very hard for him. If people know that I have this disease and he is taking care of me, they will treat him with disgust. I can't let that happen.

The last sub-theme involves the strategies to prevent or avoid discrimination and rejection. Most families managed to avoid discrimination and rejection by hiding PLWA's physical appearances, limiting social contact, and lying about diagnosis to avoid others' suspiciousness. Hiding physical appearances was easily done when the PLWAs were in the early stage of illness. It was more difficult when the PLWAs became terminally ill because people can easily see and recognize the typical AIDS appearances. One PLWAs described how she hid her skin when she went out in public to prevent suspicion from neighbors.

> I didn't get out of the house much lately, except to see a doctor. When I go out, I wear long-sleeve- shirt and long pants to cover my skin. I don't want the neighbors to see me like this. My body has changed a lot and they are already suspicious...they ask me questions.

To prevent others from becoming interested in the PLWAs' illness and to avoid suspicions, the families kept away from people and decreased their social contact with the outside world. When people asked them about the family member's illness, the families felt uneasy and tried to avoid conversation. A mother of a PLWA avoided having conversation with her friends by giving up her routine religious activities.

> I stopped going to the temples to meditate with my friends. I don't have time to go, but I also don't want to see them right now. I am afraid they will ask about my son and I will cry. I don't want to tell anybody about my son's illness.

When the PLWA's physical appearances were difficult to hide and frequent doctor visits and hospitalizations roused others' suspicions, the families would lie about the diagnosis. Cancer of various organs, brain viral infection, and TB were the most common diagnoses the families used to tell others when asked about the PLWA's illness. These illnesses were not associated with unacceptable behaviors, or had a social stigma attached to them, therefore, the families were not discriminated against or rejected, but rather received support and sympathy. A wife of a PLWA described her anxiety of lying to her employer about her husband's diagnosis.

> My supervisor at the factory came to visit him the other day. He asked what (the diagnosis) does he have? I told him that he had viral infection in the brain. He sincerely sympathized and was concerned about my husband, and told him to get well soon. I was trying to hide that he has AIDS. I was very anxious. If he (the supervisor) knew the truth, he wouldn't have felt or said what he did. He might fire me...I don't know.

Likewise, another family misled her mother and siblings about the diagnosis to avoid discrimination and rejection from them.

> My mother and my sisters understand that there is something wrong in my brain because I had a very bad headache, they don't know that I have AIDS and I didn't tell them. I know that they will feel disgusted. I told them that I have a viral infection in my brain. It is good that they don't know, otherwise they wouldn't come visit me today.

In summary, the PLWAs and their families experienced discrimination and rejection from others around them because of social stigma surrounding HIV/AIDS. Some families had direct experience whereas some anticipated what others would feel and reacted to them based on what other families experienced. Avoidance, decreasing social contact, and lying about the diagnosis were the strategies the families used to prevent or avoid discrimination and rejection.

*Concealing the HIV/AIDS diagnosis.* While PLWAs and their families used lying and avoidance to prevent discrimination, concealing the HIV/AIDS diagnosis was also a stressor. Concealing the HIV/AIDS diagnosis led to feelings of frustration and isolation, which will be elaborated on in this section.

The married PLWAs usually disclosed their HIV status to their spouses soon after the diagnosis. The couples would keep the HIV status a secret between them at the beginning, but later some revealed the information to other family members, relatives, or friends, when it felt safe for them. There was one couple that kept the diagnosis secretly between them. Despite the difficulty of keeping the HIV status a secret, they felt that they would be safer from harassment, because they both are in high ranks at work. Additionally, it was found that when the PLWAs were asymptomatic, they were likely to be successful in concealing their diagnosis from others. Interestingly, a single HIV positive man and a HIV positive wife in the study, successfully concealed the HIV status for a long time because they were asymptomatic for several years.

In general, the families were nervous and careful in keeping their secret. It was difficult for the families to anticipate people's reactions. Therefore, they preferred to be on the safe side unless they had reasons to reveal. It was found that the families determined to keep the HIV/AIDS diagnosis a secret, revealed it within a limited group of people after considering the potential benefits and risks.

The potential benefits of revealing HIV status include receiving caregiving and support, and preventing or warning about possible risk of transmission. Others are informed if it is felt that they are likely to respond positively and supportively to the PLWAs and their families. A 30-year-old PLWA revealed his HIV status to his family members because he felt that they would accept him and he would receive emotional support from them.

> I told my parents, brothers and sisters. I am very close to my brothers and sisters, they love me very much. I knew that they wouldn't be disgusted with me or reject me. They would understand me, give me courage.

A 27-year-old infected husband described his first reason to disclose his HIV status was to warn his wife that she was in danger of contracting HIV from him. His second reason was to receive caregiving from his wife when he became sick.

> I am afraid that she (the wife) contracted AIDS from me—that's why I told her. Another thing, I will need her care when I am very sick.

The following example illustrated the benefit of disclosure when there was a risk of transferring HIV to an unborn child.

> I told my wife because she was carrying our first child. The doctor said our unborn baby could have AIDS and my wife should get tested. I was very worried about giving AIDS to her and our child. So, I told her that I was HIV positive and she should have a test. After she tested positive, we decided to have an abortion as the doctor advised.

The potential risks of revealing their HIV/AIDS status were: (a) negative reactions such as discrimination and rejection, (b) a potential threat to the PLWAs' and/or family members' employment or business, and (c) a physical or emotional impact to the receiver. A 43-year-old PLWA who used to own a grocery talked about her effort to conceal the HIV status to protect her business.

> When I have my grocery, I can't let anyone know that my ex-husband died of AIDS or that I am HIV positive. Otherwise, nobody will buy things from me.

The following narratives are examples of protecting love ones from having health conditions deteriorate by learning the truth about diagnosis.

> I can't tell my parents about my wife's illness. Unlike my wife's family, they can't accept something like this. Besides, they are elderly and have health problems. They are better not knowing or being involved with our problem.
>
> My aunt's health is not good. I am very close to her because she raised me. I decided not to tell her because she will be worried and my dying will hurt her a lot.

Concealing the HIV/AIDS diagnosis effectively prevented families from discrimination and rejection. On the other hand, it produced negative effects on the PLWAs as well as their families. Concealing the HIV/AIDS diagnosis led to feelings of frustration and isolation. The families felt trapped and alone as they explained:

> It feels like we are alone in this because we can't talk to anybody. Sometimes, we sit and cry together. We only have each other for support. When we need to make a decision, we consult each other—trying to fight by ourselves.

Another family couple recapped their isolated situation.

> I avoid conversation all the time. I am afraid that they (friends) will ask a lot of questions. I don't want to lie. We spend a lot of time with each other, crying, supporting, and encouraging ourselves.

A homosexual PLWA who was being taken care of by two HIV positive friends illustrated his loneliness of not having family around when he is dying.

> My friends are really good to me and everything, but I am lying in bed here alone. I am dying without my family. I miss my family back home. I want to talk to them and tell them that I am sorry for the past. I want to tell them how I feel, how much I'm scared [crying]. I wish to see them one last time.

Despite the effort to conceal their HIV status, rumors about having a family member living with HIV/AIDS surrounded the families.

In summary, keeping the HIV/AIDS diagnosis secret was the families' goal to protect themselves from discrimination and rejection. In some circumstances, the diagnosis was concealed to protect business/employment of family members, and to protect vulnerable love ones from having health conditions deteriorate once they learned the bad news. However, most families gradually disclosed the HIV status to others to gain support, receive caregiving, and to warn others regarding transmission.

*Caregiving tasks.* Family caregivers reported caregiving tasks as their particular stressor. Caregiving of PLWAs was challenging, demanding, and often overwhelming. The caregiving demands depend upon the illness trajectory, within which the caregiving tasks can vary in each stage of HIV disease.

Most families addressed their concern for providing care to the PLWAs. Although two families had previous HIV positive member (ex-husbands), all families in this study had no direct previous experience with caregiving of a PLWA. Despite receiving basic knowledge about HIV transmission and prevention from health care providers, most families expressed their concern about not providing appropriate care to their love ones.

In most families, one family member assumed a role of primary caregiver for the PLWA; other family members provided support. Caregiving of PLWAs included a variety of activities to meet the physical, psychological and medical needs. Since the trajectory of HIV/AIDS is unstable, the families encountered caregiving challenges throughout the illness trajectory. Stressors associated with the burden of the caregiving were categorized in three types: (a) physical care, (b) emotional care, and (c) medical care.

In an early phase of the illness, physical care activities focused on maintaining good health and monitoring health. The families addressed the importance of enough rest and good food (nutritional food, food supplements, and vitamins). Family caregivers monitored and assessed the PLWA's condition, to be able to quickly detect abnormal signs or symptoms of the progressing illness. Health promotion behaviors such as quitting smoking or drinking, and maintaining regular exercise were mentioned as strategies to help PLWAs stay healthy. The goal was to keep the PLWAs in good health as long as possible to prolong their asymptomatic stage. Despite these efforts, families reported that it was difficult and stressful to maintain the health of the PLWAs. None of the PLWAs in the study received any antiviral medicine before they became symptomatic.

As the disease progressed, and the PLWA's health declined, physical care became the major caregiving task. When PLWAs were terminally ill, they needed help with activities of daily living ranging from bathing, dressing, toileting, feeding, medicating, helping with mobility as well as preventing the spread of infection to other family members. Caregivers reported that they learned about caregiving of the PLWAs from one or more following sources: (a) their own experience of caring for a family member in the past; (b) other HIV/AIDS caregivers they met; and (c) imitating health care providers by observing what they did for the PLWAs. Even though the families performed the caregiving activities mentioned above, some families in this study mentioned particular caregiving activities including feeding, medicating, and preventing the spread of infection to other family members, as the most problematic and stressful to them.

Feeding and meeting the nutritional needs of PLWAs often are stressful. All families believed that good nutrition would help with healing and increasing strength, as well as prolonging the life of PLWAs. However, feeding a PLWA sometimes caused frustration. A wife caregiver expressed her feelings of frustration regarding her husband's eating.

> I've tried everything to help him eat some food. He told me he was hungry. I went out and bought him rice soup. After three bites, he couldn't eat anymore. I knew he wanted to eat, but he just couldn't keep the food inside his body. He felt awful and threw up. I am worried that he does not get enough food to make him strong and fight the disease.

Medicating was stressful for some families. Medicating involved buying, preparing, and reminding the PLWA to take his/her medicine. A PLWA's likelihood to skip or miss pills was the major concern for caregivers. Side effects of medications and the PLWA's neurological status caused such concerns. A husband caregiver explained his stressful situation when his wife refused her medications.

> My wife refused to take her medication; she was very confused at the time. So I ground them and put them in her food. Otherwise she would miss her medications.

A mother caregiver described that her son relies on her for his medication intake.

> ...When he was at home, he was too weak to take his medication himself. I can't go anywhere too far. I must hurry back to prepare and give him medications.

Preventing the spread of infection to other family members was described as another concern for some families who were caring for PLWAs in this study. In order to protect other family members from contracting HIV as well as other communicable diseases that PLWA had, families administered several precautionary techniques including using separate utensils and personal items, and changing living arrangements such as bedroom and bathroom.

Family caregivers in particular expressed their fear of unintentional exposure while providing care to the PLWAs because they were not well equipped. Most caregivers reported that they did not wear gloves or a mask when administering care for PLWAs at home. The rationale of such practice was one or more of the following: (a) not being able to afford gloves or masks, (b) not wanting to hurt the PLWAs' feelings by implying they were disgusted, (c) not wanting others to suspect HIV status, and/or (d) not considering it necessary for HIV infected caregivers. Some families reported that they did not disinfect bloody items; they did not have enough time to disinfect or could not afford purchasing bleach. Family couples reported that they chose not to have a sexual relationship with their partner or used condoms as a prevention method, regardless of their partner's HIV status.

Families provided emotional care to the PLWAs along with the physical care. Most PLWAs reported that they needed comfort and companionship from their family members. As the PLWAs became sick, weak, and dependent, they relied on their caregivers to accompany them to doctor visits, and to stay with them during sleepless nights, painful periods, or lonely times. Some caregivers expressed their inability to meet the PLWA's emotional needs as being stressful. A friend of a homosexual PLWA described her feeling when she was caring for him.

> …as you know, he has nobody else. He was thinking about lots of things in his mind and I knew that he couldn't sleep all night. I wanted to stay up and talk with him, but I was too tired from my day job.

Many PLWAs reported that they experienced suicidal thoughts. They were thinking about ending their lives to relieve their families' burden and pain. Family members described trying to help PLWAs maintain hope as stressful. A brother of a 43 year-old PLWA stated that his encouragement inspired his sister to maintain hope for living a long time:

> "She already gave up on her life. I was afraid that she would kill herself. So I gave her encouragement that she might be cured. There will be medication that cures AIDS in the near future, and she needs to stay alive until that time. She gets encouragement to hang on, and her mind has hope. It was hard telling her that because I am not sure that she will be alive that long.

It was the goal of every family to give the best medical care to their loved one. Most of the families in this study sought out the best medical care that they thought would make the PLWA get better and prolong his/her life. Cost of care, insurance coverage, financial aid, health care providers' attitude toward PLWAs, AIDS specialized services, and location of the health care institution were the factors influencing a search for the right health care service. However, finding and maintaining quality health care was often overwhelming. Discrimination, rejection, ignorance, and disrespect from health care providers occurred despite the fact that anti-discrimination policies related to AIDS-care were implemented in Thai health care systems. In addition, dealing with the limited services in the health care institution added other stressors for families. Such challenges were long waiting lines to see a doctor, obtaining medication, and lack of beds for inpatients.

In summary, the family caregivers experienced stress in performing caregiving activities to meet the PLWAs' needs. The stress is related to the physical care of feeding, medicating, and fear of the spread of infection to other family members. Unmet emotional need of the PLWAs concerned the caregivers. Seeking and maintaining medical care was often a problem.

*Caregiver's burnout.* Burnout is another stressor that the caregivers in this study mentioned. Burnout was described by the caregivers as chronic, and fluctuated depending upon the PLWA's condition and the intensity of caregiving activities. Caregiver's burnout consisted of both physical and emotional aspects.

Physical exhaustion or fatigue is common among the primary caregivers due to caregiving overload either at home or the hospital. Because of hospital staffs' work overload, family caregivers assist their love ones with daily living activities including bathing, toileting, and feeding. Caregivers mentioned their physical exhaustion as well as emotional burn out. Visiting hours were from 6 AM to 8 PM everyday. A husband caregiver described his typical day of performing bedside care for his wife in the hospital.

> I get up very early to take a bus to the hospital to feed her breakfast and give her a bath. I stay with her during the day doing whatever she needs and leave when the nurse announces that it is time to leave. I've done this everyday for almost a month now. I am very tired; caring for her in the hospital is more demanding than at home because I have to commute everyday. No one substitutes for me.

Giving care at home was also demanding when PLWAs' health declined. By devoting time to provide care to PLWAs, caregivers reported that their personal time and activities decreased. A wife described her situation while giving care to her husband.

> He needs someone to be with him and doing things for him all the time. I wish there was somebody else to take turns with me. I am very exhausted—both body and mind. I don't have time for others or myself. My husband is the center of my life right now.

Another caregiver described the hardship of caring for her daughter at home.

> She was so weak, I have to carry her to the bathroom and stay with her, because I am afraid that she will faint or fall in the bathroom. She couldn't eat anything except light rice-soup. She couldn't walk up stairs to her bedroom, so I sleep with her on the first floor. I hardly get enough sleep, because she often has a fever and sweats in the middle of the night. Three or four days before she came here, she had a headache and was confused. I had to be with her all the times. That was a very hard time. I have no life of my own; all my time is devoted to her.

A mother was exhausted by caregiving activities that she performed for her son.

> I take care of him during the day. His father helps out when he gets back from work. I cook, clean, doing laundry for him and the whole family. I am very busy—at the end of the day, I have no energy left.

It was found that the physical strain from providing care to the PLWAs took its toll on the caregivers' health. As a result, some caregivers experienced fatigue, weight and appetite loss, and sleep deprivation. An elderly caregiver reported that her pre-existing heart problem was exacerbated while providing care for her son. A single mother caregiver noticed negative changes in her health after taking care of her son for a month in the hospital.

> I am very exhausted. Lately, my body can't endure this kind of hard work. Coming here (hospital) everyday, I don't have energy left at the end of the day. I don't eat and sleep well. I lost some weight too. Everybody told me that I look skinnier and sick.

Although some caregivers reported that their health deteriorated from caregiving, they prioritized the health of the PLWA above their own. For instance, a HIV positive husband postponed his medical needs to focus his attention and resources toward his wife. He explained that his wife's health and illness are the primary concern at the time, because she was more seriously ill, compared to him.

Caregivers reported emotional burnout as a result of dealing with the PLWA's behavioral and emotional changes. Some PLWAs had neurological symptoms that caused behavioral and mood changes. Several caregivers reported that they experienced PLWAs' frequent emotional irritation and aggressive behaviors.

> I went out and bought different kinds of food he likes when he has some appetite. When I couldn't find what he wanted to eat, he was angry and threw stuff at me. I was very frustrated and felt sorry for myself. When he was aggressive toward me, I cried even though I know that it is his illness that makes him do that.

In summary, caregivers experienced both physical and emotional burnout from daily caregiving activities. Consequently, the caregivers' health was jeopardized.

*PLWA's uncertain health status.* AIDS is a chronic illness. In some cases PLWAs can live for several years depending in part upon how well they take care of themselves. Additionally, HIV/AIDS is characterized by a collection of complex syndromes. Most PLWAs had multiple opportunistic infections as they approached the terminal stage of AIDS, which led to fluctuations in health status. Some families mentioned that they were very stressed because of the PLWA's unpredictable health status. Families experienced some degree of uncertainty as well as loss of control of the PLWAs' health condition and symptoms. As a result, the families became vigilant in monitoring and managing symptoms to quickly acquire treatments.

One PLWA was terrified when he found out that he was not one of the patients who lived years before developing AIDS related symptoms. He expressed his feeling of disappointment in his unexpected illness episode and feeling of a loss of control over his illness.

> The doctor said I might not have symptoms for years if I take good care of myself. So, I took care of myself from the beginning when I had not developed any symptoms. I watched what I ate-not eating red meat or preserved food. I exercised and took vitamins, and even quit drinking and did not go out in public places where there are lots of people, to avoid germs. But that did not seem to help. A few months after, I was very sick and hospitalized with TB and then this- another disease (meningitis). I was fine not long ago, and I was determined to keep it that way as long as possible. I never thought that my health will get worse so quick, and one thing came after another like this. This disease, you can't tell what it will do to you…you'll never know. I am disheartened and now I feel that I can't do anything to prolong my life. I am hopeless… (Eyes fill with tears).

A wife caregiver explained her husband's health fluctuated between sickness and recovery.

> His condition is up and down. He was better for a while and then became sick again. He was not fully cured and had not returned to a normal life. That worried me the most. I don't know when he will be sick again, and how serious it will be. The only thing I wish is that he is not too weak to fight that.

At this hospital, the regulation regarding patient visiting does not allow the family to stay with a patient after visiting hours. One family member recapped the family's uncertainty and fear of losing their love one while she was in a critical condition.

> We all were afraid that she might die in the hospital when we are not there with her, when she has her last breath. She was severely ill and that made us worried. When we left her every night, we were terrified and uncertain realizing that we may or may not see her alive when we came back in the morning. It is very uncertain when a patient is in critical condition like that.

At the time of the interview, most of the PLWAs had received treatment in the hospital for a while. They felt better and were soon close to being discharged from the hospital. However, they still expressed concern about their uncertain futures. Most families mentioned hope that their loved ones would get well enough to live long and normal lives. A PLWA explained that he would maintain hope after leaving the hospital despite the uncertainty of his illness.

> I will be able to go home next week, the doctor said. I'm still not sure about my future… how well my health will be from here. But we believe that there will be a medication that can cure AIDS soon. I just have to hang on until that time comes. I hope that I can wait.

PLWAs who were currently employed expressed concern about holding their job while their health was deteriorating and limiting their ability to go to work and to perform. A PLWA who was a sales person, and whose job was to ride a motorcycle around the city all day, described his worry about his long-term health status:

> I am afraid when I go back to work, I will get sick again because I ride my motorcycle all day. The air is hot and polluted. Even when I was fine, I felt terrible when I go home at night. Now that my immune system is low, I get sick easily. I'm not sure I have enough strength to do the job again ever. It depends on how healthy I am when I go home.

In summary, the families struggled in dealing with the unpredictable health condition of the PLWAs. The PLWAs and their families reported uncertainty about the prognosis, death, the long-term health of the PLWAs, and ability to work as stressful.

*PLWA's emotional suffering.* Emotional suffering is a family stressor described from the PLWA's perspective. Some PLWAs described that they are suffering emotionally by living with feelings of guilt, shame, and sin. Because their mode of AIDS transmission was from promiscuous behaviors like visiting prostitutes, the PLWAs were ashamed of their behaviors. A PLWA stated:

> I didn't listen to my parent's warning about visiting prostitutes, so I am dying like this. I feel shame for what I have done.

In family couples, the PLWAs felt responsible for passing HIV to their spouses. A HIV positive husband expressed his feeling of guilt.

> I destroyed our family. It is my fault--not her fault.

Most PLWAs felt guilty because they became a burden on their families. This feeling of being a burden was significant when the caregivers were parents. A HIV positive son described his feelings of guilt and identified himself as having sinned by hurting his parents' feelings.

> They (parents) are old; they shouldn't have to take care of me. I make them sad and put them in so much pain. I am a sinful son. It is a great sin to hurt your parents.

It was concluded that in addition to physical suffering, the PLWAs experienced emotional suffering. Feelings of guilt, shame, and sin were the most common emotions among the PLWAs.

*Struggling with the health care system.* Another stressor involved families' struggle to seek resources and obtain services from the health care system. Although there are several HIV/AIDS resources and services available for PLWAs and their families, the system is not well established in the Thai health care system in a way that it offers standard assistance and equal accessibility to all families living with HIV/ADIS. Examples of resources in the Thai health care system are public health care institutions, including the study hospital as well as non-profit organizations. The services range from HIV testing, counseling, education, treatment, rehabilitation, financial/living assistance, and hospice care.

All families confirmed that they were facing difficulties when caring for PLWAs having no or few resources and support services from the health care system. It is evident that most families received insufficient assistance simply because they did not have knowledge of the kind of help available. The following account reflected that families did not know what to do and were hesitant.

> I never had a family member with a deadly disease before. I have no idea how to care for him. Nobody told me how to take care of him when he was discharged from the hospital... We are not rich people, money is a problem... I think I could use some help with money and advice about caregiving, but I don't know that there was help until

> you (the researcher) told me. I don't know much about how things work around here (hospital)… I don't dare ask them (health care provider).

Asking for social welfare was the most minimal support that some families received, however, it was the most problematic. Because of the limited social welfare budget, families sometimes had to be aggressive in negotiations to obtain social welfare benefits.

> I heard from other patients that you could use social welfare to pay for medication and hospitalization bills. So I went there and had a fight with that female social worker. She asked, "Why don't your relatives help?". She didn't believe that I couldn't pay the bills. She asked me how much money I had left. Then she told me that I have to pay for the hospitalization bill, and social welfare will pay for the drugs.

A few families reported that they received the services previously mentioned, depending on their opportunity and ability to access the resources and obtain the services. Confidentiality was a major factor that influenced the families' decision to seek services. Fear of being shunned or creating suspicion about HIV status forced the families to consider whether or not to receive assistance and services.

Another struggle with the health care system involved a hospital's admission policy. Some hospitals have a policy that limits the number of HIV/AIDS patients they will admit. Refusing to admit PLWAs is common in Thailand. The patients are given emergency medical treatment and then referred to other hospitals despite the patients' unwillingness. In turn, the referred hospitals try to avoid responsibility for these patients. One family was caught in the middle of this battle. The patient was refused admission by the hospital where he was first diagnosed and was treated in another hospital. He was referred to that hospital and admitted to receive medical treatment, and was then told that he would eventually be sent back to the first hospital for long-term treatment. The patient's father described the uncertainty about his son's medical care.

> Last night my son was having a severe headache, we took him to that hospital because he tested HIV positive there eight months ago. They gave him some medication, but said there was no bed available to admit him. Then, they transferred him here. The doctor here was angry that they did that, and wanted to send him back to that hospital. Every hospital refused to take him because he has AIDS. It isn't fair. We begged the doctor to keep my son here, but we are not sure what the doctor is going to do with him. We don't want him to start over with the treatment again, we want him to have a good doctor and get good continuous treatment here. Right now, I don't know what will happen to his future treatment.

In summary, most families received insufficient assistance and support from the health care system, and struggled to obtain the services they needed from the health care system. Learning about the system, and seeking and negotiating to gain assistance were stressful and often unsuccessful.

*Planning for impending death.* In addition to dealing with uncertainty of the PLWAs' health condition, planning what to do in the future occupied the minds of the PLWAs and their family members. The complexity and uncertainty of the AIDS illness trajectory led the families to learn to think and plan about what they would do when the PLWAs were in the terminal stage, and after the death of the PLWAs. However, the plan could change depending upon the situation and health condition of the PLWAs. At an early stage of the AIDS trajectory, the families decided whether they needed to arrange accommodations for appropriate housing, such as more private housing to avoid suspicion, and easy accessibility to health care facilities, caregiver, or other family members. When the PLWAs began to have symptoms of opportunistic infections, the family considered where the hospice care would take place and who would assume the responsibility of caregiving. In addition, the families planned to alert their loved ones to prepare for a possible death when the PLWAs became critically ill. Since the cause of death could lead to social discrimination and rejection of those associated with the PLWAs, the location of death and careful funeral planning were discussed when the PLWAs' death was certain. The families reported that they made agreements concerning what to say when they were asked about the cause of death of the PLWAs. Life threatening diseases that have less stigma such as skin cancer, leukemia, tuberculosis, and meningitis were the most common causes of death that families chose to reveal to others, to prevent people's suspicion of HIV/AIDS.

According to the participating families, plans for the living family members after the PLWA's death were made. They made decisions about who would take care of their family, especially the children and the HIV positive spouses. Moving back to hometowns with parents or siblings was a common option for the HIV positive widows.

> The most bothersome thing in my mind is whether my wife will have somebody with her when she becomes ill. She took care of me and she deserves to have somebody takes care of her. She plans to go back to her hometown with her parents after I'm dead. I hope they will welcome her and not feel disgusted with her.

It is noted that, generally, Thai people feel uncomfortable about discussing death and funerals before they happen, but the impending death and stigma attached to AIDS forced the family to consider options that least affected the living family members.

> It's bad luck to talk about death, but I know that I will die eventually, so my brother and I talked about my funeral...we chose to have a short funeral where my body will be cremated within 3 days (number of days before cremating ranges from 3 to 100 days). We selected the temple that is in a remote area where we trust they won't reveal about AIDS. He will tell others that I died from cancer. We have to lie to protect my children.

In summary, the families felt the need to plan for an impending death of the PLWAs. Negative effects of AIDS did not end after the PLWAs' death, but continued to affect the family members left behind. The PLWA's goals were to take the best care possible of their family members and protect them from social discrimination and rejection.

### *HIV/AIDS Non-associated Stressors*

Every family had stressors or problems in their daily life. Besides the stressors related to HIV/AIDS of their family member(s), the families in the study reported the stressors related to normal daily family life. The following were stressors that the families mentioned as stressful, but not directly related to HIV/AIDS: children's behaviors, financial law suits, previous debt, marital relationships, health/illness of other family members, housing problems, family member's career/business/work situation, insufficient family time because family members overworked, and family historical conflicts. While the families experienced

HIV/AIDS non-related stressors, the researcher chose not to elaborate on them, as it is not the primary focus of the study.

In summary, the study purpose is to identify family stressors that Thai families perceive when their family members have HIV/AIDS. Data analysis shows that several stressors related to HIV/AIDS occurred. Nine categories of HIV/AIDS related stressors emerged: financial burden, discrimination and rejection, concealing the HIV/AIDS diagnosis, caregiving tasks, caregiver's burnout, PLWA's uncertain health status, PLWA's emotional suffering, struggling with the health care system, and planning for impending death. A summary of the categories and sub-themes of these stressors is presented in Table 5. In addition to HIV/AIDS related stressors, the families continued to have other stressors, which relate to normal daily family life, occurred.

Table 5

*Family Stressors: Categories and Sub-themes.*

- ◆ *HIV/AIDS Associated Stressors*
  - ■ *Financial burden.*
    - A. Leading factors of financial burden
      - Cost of HIV/AIDS medical care
      - Lost of family income
      - Cost of transportation to health care facility
      - Caregiving related expense
    - B. Strategies to maintain financial status
      - Using savings
      - Borrowing money
      - Seeking social welfare
  - ■ *Discrimination and rejection.*
    - A. Leading factors of discrimination and rejection
      - Social stigma due to the negative public campaign
      - Physical appearance of AIDS
      - Superficial or inaccurate knowledge about HIV/AIDS
      - Unacceptable behaviors association with HIV/AIDS
    - B. Actual experience of discrimination and rejection
    - C. Anticipation of discrimination and rejection
    - D. Strategies to prevent or avoid discrimination and rejection
  - ■ *Concealing the HIV/AIDS diagnosis.*
    - A. Potential benefits
    - B. Potential risk
  - ■ *Caregiving tasks.*
    - A. Physical care
      - Feeding
      - Medicating
      - Preventing the spread of infection to other family members
    - B. Emotional care
    - C. Medical care
  - ■ *Caregiver's burnout.*
    - A. Physical burnout
    - B. Emotional burnout
  - ■ *PLWA's uncertain health status.*
  - ■ *PLWA's emotional suffering.*
  - ■ *Struggling with the health care system.*
  - ■ *Planning for impending death.*
- ◆ *HIV/AIDS Non-associated Stressors*

## *Family Strengths*

To answer the research question, "What are the family strengths which help Thai families to cope with the stressors when one or more family members have HIV/AIDS?" family members were asked the following question: "What are the strengths that have helped you in dealing with the problems and stressful situations?". The findings pertaining to family strengths are reported in this section.

Families' strengths depended upon their particular background, such as family composition, relationships, beliefs, and values. The strengths that the families mentioned in the study included religious beliefs, strong sense of family obligation, sense of forgiveness and understanding, emotional connection, receiving social support, maintaining hope, family working together, diverting attention from HIV/AIDS, and focusing on the present. Each strength is discussed in detail next.

### *Religious Beliefs*

Most families mentioned religious beliefs as providing the most helpful and frequently used resource. In Thailand, Buddhism deeply influences the way of thinking and living life. Therefore, Buddhist religious beliefs play an important role in coping with the stressors of a family living with HIV/AIDS.

It was found that the Buddhist faith helped families cope with the premature death of their loved ones. Families mentioned that they found comfort and strength from the Buddhist religious notion of embracing death as natural part of human life. Buddhism views death as unavoidable and that everyone must die. Thus, Buddhist teachings encourage a person to accept and welcome his/her death whenever it comes. A 43-year-old PLWA described her Buddhist faith regarding death as helping her to accept her death.

> I believe that (Buddhist) religion helps a person accept bad things that happen in life… I am not afraid of death. Everybody must die eventually…they just don't know in advance when and what they will die from.

Buddhist teachings also encourage one to endure the circumstances or sufferings in terms of karma and their previous deeds. A basic premise underlying Buddhism is that things or events that occur in one's life are beyond his/her control, but rather one's life is controlled by his/her karma which is based on a balance of one's own past merit and sin. Karma is viewed as inherited from a previous life and as a store of rewards and punishment, which must be enjoyed or endured. According to the families in this study, suffering and dying from a deadly and stigmatized disease such as HIV/AIDS were attributed to their karma. They believed that they were supposed to repay previous bad deeds. This belief provided a rational and inner strength to some families, as they viewed their life as being controlled by their karma when trying to explain why things had happened in their lives. This belief helped decrease their stress and gave them a sense of peace through accepting their state of being, and by not thinking about, or paying attention to, things that they cannot change or control such as HIV or death. The following narrative reflected those beliefs.

> …Because it (HIV infection) happened already, we can't do anything about it, but to accept it as a repayment for our own karma. I have done good thing in my life, so this won't get any worse.

When seeking an explanation of his HIV infection, a homosexual PLWA claimed that his infection is because of his karma. He felt that his past bad actions contributed to his misfortune.

> I believe it is my karma to suffer and die. I did bad things. I passed AIDS to many people. My bad karma is catching up with me now.

Buddhist religion provided strength to one participant in a personal way. Buddhist institutions offered a safe place for emotional/spiritual healing and supports. A 29-year-old PLWA sought out a sanctuary by entering a monkshood for a few years after he tested HIV positive. Total devotion to studying Buddhism helped him cope with his stress and gain mental strength and inner peace.

> Studying Buddhist's teachings and practicing rituals as a monk helped me get though the tough time. It prevented me from suicide. I was scared, confused, and hopeless. Monkhood is a very peaceful life. I learned a great deal about the nature of life and spiritual healing. Buddhism helps me lead my life with awareness and acceptation of all the bad things.

Some families who needed comfort and strength mentioned praying and asking for a blessing. A mother of a PLWA said:

> I prayed to the Buddha statue in my temple to protect and bless us. I believe that he will bless and help me and my family be strong.

Some families gain emotional strength by engaging in merit-making activities and meditating (doing good deeds to balance their sins). The informants described that making merit made them felt good. They believed that it improved their karmic status, and hopefully altered their present life, as well as made the next life better. Merit-making activities mentioned in the study included participating in religious rituals and ceremonies, feeding Buddhist monks, releasing captured animals, and donating money and time to people in need. One female PLWA described that meditation decreased her stress level and gave her a peace of mind as well as physical benefits such as decreasing her insomnia. A mother found that her faith was a source of strength to cope with her son living with HIV/AIDS.

> Going to the temple to pray, meditate, and make merits made my mind at peace. I came back strong and was able to deal with things in my life. It is good for me that I can accept what happened and have courage to live on and does what I need to do for my son…I saw my son suffering, and it makes me angry. When I was very sad and angry, I went to the temple and joined the ritual ceremony. It created peace in my mind and helped me be mentally strong.

### *A Strong Sense of Family Obligation*

For most illness, a sense of obligation encourages Thai families to willingly provide care for their ill family members rather than creating resentment or burden. For the studied families in particular, their willingness to give care was derived from a strong sense of obligation. Despite the social stigma attached to HIV/AIDS, and the stress and burden related to caregiving, all ten families put themselves at risk of being associated with the PLWA.

Due to HIV/AIDS stigma, some PLWAs have been neglected. The researcher did not find that to be true in this study. All families put themselves at risk and had a strong sense of obligation to care for the PLWAs. Being a father, a mother, a wife, a husband, a brother, and a sister of the PLWA engendered a sense of duty to take care of a sick family member as reflected in the following narratives:

> I taught him not to visit prostitute because it is a sin. He didn't obey me. But no matter how angry I am, I still love my child. As a mother…any mother always takes care of her child regardless of his bad behavior. I can never abandon him. It is a mother's duty.

A caregiver described his feeling of responsibility in taking care of his sister.

> I can't let her die alone, she is my sister and it is my duty to take care of family members. I feel sorry for her. She doesn't have anybody else to rely on and right now she needs me to help her get through this.

### *A Sense of Forgiveness and Understanding*

Another family strength reported by the families, particularly family couples, was a sense of forgiveness and understanding. This strength facilitated the spouses to accept and care for a HIV positive partner. In this study, male PLWAs claimed that sexual contact with prostitutes before and/or after marriage was the mode of HIV transmission. Female spouses illustrated a strong sense of forgiveness and understanding of their husband's promiscuous and irresponsible acts. Female spouses expressed their understanding of a male's desire for sexual activities with other women. This idea is consistent with the Thai view of men's nature to visit prostitutes, as "this is what men do". The female spouses perceived that their husbands' act was forgivable because they unintentionally contracted HIV, and they both were victims of his innocence. The lack of knowledge about AIDS and unawareness of potential transmission deserved forgiveness. The following narratives reflect those attitudes.

> It is common for men to want to visit prostitutes. We cannot stop them. Although it is not appropriate when one is married, I don't view it as serious wrongdoing.
>
> I was angry that he was visiting prostitutes, but he didn't realize that he could contract the virus at the time. He didn't know then that he had it and unintentionally gave it to me. He didn't intend to hurt or kill me—for that I can forgive him.
>
> He was promiscuous and did not protect himself...that I don't like. But he's already punished enough (crying). He's in so much pain. I pity him rather than hate him.

Some spouses addressed the reasons that led them to forgive their HIV positive partners. These included: (a) sense of responsibility for passing HIV, and (b) the PLWA's good behavior and relationship to the family in the past. The following narratives were examples of those two reasons.

> She is a good person and it isn't her fault that she has AIDS. It is my fault. I feel guilty because I gave AIDS to her. I must be responsible for my bad action.
>
> He was very good to me since we were married. He is a well-behaved husband who is always a giver to his family. He deserves good care back.

### *Emotional Connection*

Besides a strong sense of family obligation, some families reported an emotional connection between family members that helped the families continue providing care to their love ones. Emotional connection included a sense of love, affection, compassion, closeness, and a deep emotional bond among family members. The findings suggested that the couples that were both HIV positive did not blame their partners for passing the HIV, but rather dealt with the crisis, and developed strong emotional connections between them. Openly talking, sharing and listening to each other's experiences and feelings was reported by the families as strengthening their emotional connection. They shared their negative feelings of being overwhelmed, frustrated, discouraged, and fearful as well as the positive feelings of love, passion, sympathy, and gratefulness. Two couples reflected the emotional connection with their partners as follows.

> I felt close and more connected to him than before. We start talking and listening more to each other feelings since he was diagnosed. We talked a lot about everything…our lives, marriage, and our family's future. We are united to get through this unfortunate situation.
>
> He confessed that he was unfaithful and he felt guilty about it. He sincerely admitted that he was wrong…I love him for that. (We are) so close that we share our feelings knowing that we do not need to hide anything. He always tells me how he feels.

*Receiving Social Support*

The analysis showed the overlap between family social support and family strength. In this study, receiving social support was described as helping the families deal or cope with their problems caused by HIV/AIDS. According to the families' perceptions, receiving social support fits the definition of family strength: the abilities and resources that are used by families to solve problems and cope with stressors (Hanson & Mischke, 1996). Therefore, the concept of social support was not explored separately as proposed at the beginning of the study, but was categorized as one of the family strengths.

Although social support was defined as an ongoing pattern of social relationships between the family and its social environment that reflects interdependence, the operational definition in this study was derived from the work of House (1981). According to House, social support was defined as being comprised of four types of support: emotional, appraisal, informational, and instrumental supports and each category is viewed in relation to the source of support (social network), problem orientation, and perception of support. Two components of social support: a) source of support, and b) type of support were the focus in this study. Information regarding social support were obtained from the ecomap and the semi-structure interview guide Question 10. The ecomap, which graphically portrayed the supportive relationship between families and their communities, provided the information regarding sources of social support; whereas the semi-structure interview provided the information regarding types of support.

The analysis revealed that social support mentioned by the families came from two sources: a) inside the family (internal social support), and b) outside the family (external social support). There were different family compositions in the study including nuclear and extended families in which their members were defined by the PLWA. Some PLWAs included their parents or siblings as their family instead of as extended families. Therefore, parents or sibling who were family members were internal sources of support, whereas, parents or siblings who were not identified as family members were the extended family and viewed as external sources of support.

*Internal social support.* Most families mentioned that they received support from their own family members such as spouses, parents, siblings, and children. The family members provided informational, instrumental (tangible), and emotional supports. Instrumental support mentioned included childcare, cooking, cleaning, running errands/business as well as financial and caregiving assistance. Informational support included providing information about treatments, caregiving, and health care facilities to the PLWAs. Although family members provided various types of support to the PLWAs and to each other, emotional support was described as the most important and needed. Emotional support included being there for each other, expressing deep caring, concern and sympathy, and giving encouragement to the PLWAs.

Some PLWAs in the study emphasized the important of having the family there for them. The PLWAs stated that they were fortunate to have family members there to help them overcome the physical, emotional, and social challenges brought on by HIV infection. In particular, the presence of their loved ones was comforting when the PLWAs were suffering from sicknesses. A 43-year-old PLWA who was a single mother of three children was overwhelmed by her son's presence and encouragement. She described her feelings with teary eyes.

> He (son) visits me everyday. I am glad that he is always beside me (at the hospital). Even though he can't help much with the bedside care, having him with me makes me happy. He consoled me, even though he was sad, by telling me "mom…don't worry much about us (her three children), please take care of yourself….so we can go home, we love you." I can't tell you how much it means to me…it keeps me going.

Some families emphasized the importance of giving encouragement to the PLWAs, to reassure that they did not burden the family, and they are loved and wanted. Encouragement that came from the families who loved them promoted the emotional strength of the PLWAs. A mother of a 25-year-old PLWA explained:

> Everybody needs encouragement. A HIV infected person needs even more encouragement. Our family was there for her and encouraged her everyday. It is particularly difficult when she was very sick and in pain. She sometimes was discouraged. We make sure she knows that we love her and care for her. It is important that we are with her at every step and share her experiences and feelings.

*External social support.* Family members heavily relied on each other for various kinds support to solve the problems and cope with the stressors. However, they also sought support from resources outside the families. The family's external sources of support cited in this study included: (a) extended families (parents and siblings); (b) friends; (c) neighbors; (d) health care professionals; and (e) HIV/AIDS organizations. Each source offered a different type of support including emotional, instrumental (tangible), and informational support.

Some families, who had close relationships with their extended families, disclosed the HIV diagnosis to them. The extended families deeply sympathized with the patients and became a significant source of support for the families. In some families, the HIV diagnosis was concealed from the extended families to avoid discrimination and to maintain assistance and support from them.

In this study, the extended family members were persons who were related by blood or marriage but not defined by the identified patients as part of the family unit or caregivers. The following findings derived from those who fit the category of extended families.

Extended parental support was the most frequent use of support mentioned in the study. Some families said that their extended parents gave them both emotional and instrumental support. The instrumental (tangible) support included providing material goods, money, and shelter; providing help in caregiving; assisting with household chores; providing transportation; and searching for alternative treatments. The emotional support included visiting the patient in the hospital or at home; making a phone call to express their concerns; listening; and giving encouragement, comfort, and hope. The following paragraphs were the examples of the families who received assistance and support from their parents. A husband of a PLWA described the support they received from his wife's father.

> My wife's father calls all the time to see how he can help. He told us to not give up. He said he want to help take care of his daughter at the end of her life and asked me to take her to his house in her hometown. I have to say he is a very supportive father…I am very grateful.

A 28-year-old wife pointed out her appreciation of help and supports from the mother of her husband.

> His mother is a big help with taking care of __(the PLWA), preparing his meals and finding new drugs (herbal remedies) to treat AIDS. Whenever there was a rumor that they had drugs that could cure AIDS, his mother went there and brought back all kind

> of herbs. She always encourages us to keep hoping. Her help and supports mean a lot to us. We wouldn't make it without her.

A mother of a PLWA described how she gave her son emotional support.

> The only thing I can do is encourage him (her HIV positive son). I comfort him when he is down. I repeatedly tell him that we will always be by his side and help him get through this.

Very few families mentioned extended siblings as sources of support. Because of poverty, physical distance and the responsibilities of their own families, the only type of support they could give was emotional support to the family. That support included visiting the patient in the hospital and making phone calls to express their concerns.

The majority of families did not received support from friends. Most families were not sure about the reaction of their friends, if they knew about the HIV diagnosis. Therefore, they decided not to reveal the diagnosis. As a result, most families did not receive support from friends. Only one family mentioned friends as a source of support. Friends gave them emotional support such as comforting phone calls and visiting at the hospital and/or at home; instrumental support such as loans; and informational support such as giving advice on caring for the PLWAs.

Only one family received support from their neighbor since most families did not reveal the illness of a family member to them. This particular family trusted the neighbor enough to tell her about the diagnosis and received financial support and housing assistance from her.

Health Care Providers such as physicians, and counselors were another source of support for the families. The support from the health care providers mostly included informational support, such as treatment options, self-care information, and health care services and resources. Most PLWAs reported getting information about HIV/AIDS from their physicians rather than other health care professionals. None mentioned receiving support from nurses. A few PLWAs received emotional support from their physicians and counselors. One family described the support they received from their physicians.

> My doctor is very supportive. He spent time explaining to me about AIDS and how to live my life with the disease. He told me about treatments and how to live with AIDS.

The couple who made decision to terminate the pregnancy after diagnosed with HIV positive said:

> Our doctor was supportive when we decided to have an abortion. He was very kind and comforting. He assured us that it was the best decision.

Two families mentioned that they received support from HIV/AIDS organizations. The organizations were established to offer various supports for the PLWAs in the community. One PLWA was involved with the organizations since he was first diagnosed and was introduced to the organizations by his physician. The instrumental support that the families received were housing, financial, and job assistance. The organizations also provided emotional and informational support through counseling services and AIDS support group programs.

Among the different types of external support mentioned in the study, the families pointed out that the emotional support was the most important to them. Families expected to have people around them express their concern and care, give encouragement and comfort, or merely listen to them. For some families, there was limited emotional support from their social network due to an avoidance of disclosure. A husband of the PLWAs shared his feelings of isolation and loneliness.

> I know she (the PLWA) needs someone to support and comfort her, but sometimes I was sad and scared too. One day I walked out on her and went home to sit and cry alone. It is too much to handle. I was overwhelmed. When I am in that state, I can't be with her and encourage her. I need some encouragement and support myself…and there is no one there.

It is obvious that some families had limited external social support because they decided to keep the HIV status hidden to avoid stigmatization and threats. However, some families received support from their communities because they disclosed false diagnoses. One family pointed out the benefit of gaining support as a result of lying about the illness. The family told their friends and co-workers that the PLWA had lung cancer.

> When he was admitted in the hospital, I call his work for a sick leave. We decided to tell his co-workers that he had lung cancer. We can't tell the true diagnosis because he may lose his job and that would make things harder. It turned out that everyone in his office is very supportive and encouraging. His co-workers take over his work while he is absent. Some pay visits here (the hospital) wishing him to get well soon. I am glad that we didn't tell them the truth and received the supportive responses.

One family expressed uncertainty regarding the support they received now if they disclosed the HIV diagnosis. The PLWA's siblings were told that their sister had a viral infection in her brain.

> All of them (siblings) were worried about me. They all came to visit me here (hospital) to show their support yesterday. They comforted me and sympathize with me. I don't think I would get this if I told them that I have AIDS. They would be afraid of me and wouldn't want to do anything with me.

In summary, the majority of families relied on their family members for support; however, some families received external support from their extended family and health care providers. Few families received support from friends, neighbors, and AIDS organizations. None reported support from co-workers. The type of support provided by the family social network included emotional support, instrumental support, and informational support. It was found that several families had limited support while dealing with stressors caused by HIV/AIDS, because of the concern for discrimination and rejection from the communities.

*Maintaining Hope*

Another strength that most families mentioned was maintaining hope as well as positive attitudes. The families maintained their hope of finding alternative treatments that would save their loved ones' lives. All families had hope for the discovery of Western medications that could cure AIDS in the near future. They were also hopeful that the PLWA's illness would not get worse and they would have prolonged lives. A 30-year-old wife expressed hope as her strength to cope with difficult times.

> (We) live with hope. Hope gives one a will to live and to take care of oneself. I told my husband to take good care of himself and wait for the cure. I am very hopeful that soon there will be medication that can cure AIDS. He said that he has a strong will to live as long as possible.
>
> I just wish I live long enough to see my children grown up, but my brother has high hope that I will be cured eventually when they find the drug to treat AIDS. That thought is very encouraging… I can tell you that.

Some families also thought positively about their future; wishing that a miracle or good things might happen to them. A husband described his coping strategy of maintaining hope and positive thinking.

> She is a good woman… she never did anything bad in her life. May be there will be a miracle. We tried everything people told us that cures AIDS. There must be something out there that can kill the HIV virus. We can't rely on western medicine; we have to keep looking for the alternative treatments. I think this hope encourages us to fight.

### *Family Working Together*

Family members worked together to overcome stressful situations. They gained strength through the sense that they were a family unit that helped each other in a time of need. Facing the tragic event forced family members to reach out to one another and work together to solve their problems, make decisions, and plan for the future. The issues where family members worked together on solving family conflicts, adjusting lifestyles, caregiving, searching for health care, making decision, and protecting the family from social stigma related to HIV/AIDS. A 29-year-old PLWA expressed his appreciation for his family as they all were working together to help him.

> I trust no one but my family. I know they want the best for me and they are great. We brainstormed and formulated a lie about my illness, and when and whom we told about it. They helped me run the laundry business and errands, so I didn't have to go out of the house and be seen by others. My family involves in making decisions about my treatment and everything. I can't do this without them.

*Diverting Attention from HIV/AIDS*

To deal with stressful situations, some families mentioned that they diverted their attention from HIV/AIDS. They tried to occupy their mind by constantly doing other activities such as watching television, petting animals, gardening, talking, performing house chores, and working. For example, a HIV positive woman described how she occupied her day with daily house chores to keep her mind off HIV/AIDS.

> I was so depressed while confined in the house (to avoid neighbor suspicion). I thought I must keep myself busy. I can't sit and think about this all day. There is a chance of suicide if I do that. I did everything in the house—cooking, cleaning and laundering for the whole family. I also knit…I love to knit. These things prevent my mind from thinking about the disease I have.

### *Focusing on the Present*

A few families mentioned that they get through their every day life by focusing on the present and what needed to be done. In contrast to maintaining hope, some families accepted with bravery the reality of dying and living their life day by day. One PLWA felt that he gained strength by setting his mind on the present moment rather than the future.

> I am at the point that I don't think far ahead about when and how I will die. I concentrate on today and deal with today's problems. If I think a lot, I worry a lot, and that is not good for me.

In summary, the study's purpose is to identify family strengths that help Thai families cope with the stressors when family members have HIV/AIDS. The data analysis shows that all families were able to draw upon their family strengths to help them cope with living with HIV/AIDS. Some families employed more strengths than others. The identified family strengths were religious beliefs, strong sense of family obligation, sense of forgiveness and understanding, emotional connection, receiving social support, maintaining hope, family working together, diverting attention from HIV/AIDS, and focusing on the present. A summary of family stressors and sub-themes is presented in Table 6.

Table 6

*Family Strengths: Categories and Sub-themes*

- *Religious Beliefs*
- *Strong Sense of Family Obligation*
- *Sense of Forgiveness and Understanding*
- *Emotional Connection*
- *Receiving Social Support*
  - *Internal social support.*
  - *External social support.*
    - A. Extended families
      - Extended parents
      - Extended siblings
    - B. Friends
    - C. Neighbors
    - D. Health care providers
    - E. HIV/AIDS organizations
- *Maintaining Hope*
- *Family Working Together*
- *Diverting Attention from HIV/AIDS*
- *Focusing on the Present*

Another question asked in the interview was to assess the family's needs. The next section is the summary of the answers responding to the question of family's needs in the semi-structure interview guide.

### *Family's Needs*

At the end of the interview, the families were asked, "What do you and your family need/want to help you cope with HIV disease in your family?". The families' responses were primarily in the area of their needs for social support services that are designed specifically for families. These social support services included informational support, instrumental support, psychological support, and home care support.

Due to the lack of knowledge and proper understanding about HIV disease and how to care for the PLWAs, the families had little confidence in themselves to take care of the PLWAs, especially when the disease progresses. The families wanted to be more educated by their health care providers. Educational programs that offer information about HIV disease and caregiving practices were the most desired. In addition to the informational support, instrumental supports were also needed. Financial assistance is the most needed, followed by caregiving supports, such as supplies and home care services.

Most PLWAs experienced emotional distress and suicidal ideation while the caregivers often experienced stress and depression. Family members also dealt with stress due to fear of discrimination and rejection from being associated with the PLWAs. Arising out of these experiences, the need for psychological support, such as counseling and support groups for the PLWAs and their families, was reported.

## Conclusion

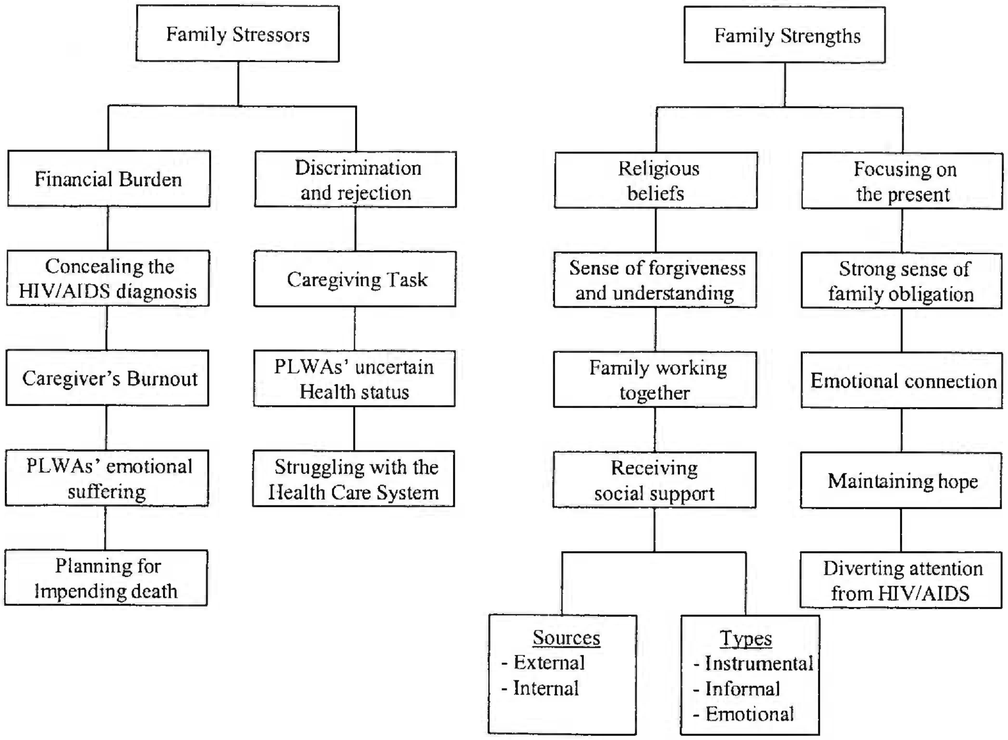
The study findings were based on a total of 31 primary informants from ten families living with HIV/AIDS. Data from patients' chart reviews, genograms, ecomaps, and the semi-structured interviews were used to develop family profiles and answer three research questions regarding family stressors, strengths, and social supports. The family profile section was presented for better understanding of each family and its context.

The purpose of the study was to answer three research questions. The first research question was: What are the family stressors that Thai families perceive when one or more family members have HIV/AIDS? The semi-structured interview guide was used to obtain the information regarding HIV/AIDS related stressors and HIV/AIDS non-related stressors. The HIV/AIDS related stressors identified by the families are summarized in Table 5. The HIV/AIDS non-related stressors identified by the families included wanting to have offspring, children's behaviors, financial law suits, housing problem, previous debt, health of other family members, family members being overworked, family conflicts, marital relationship, family's chores/business, and family member's job and career.

The second research question was: What are the family strengths that help Thai families cope with the stressors when one or more family members have HIV/AIDS? The semi-structured interview guide was used to obtain the information regarding family strengths. The strengths identified by the families are summarized in Table 6.

The third research question was: What are the family social supports which help Thai families deal with the stressors when one or more family members have HIV/AIDS? The semi-structured interview guide and ecomap were used to obtain information regarding family social support. The families described receiving social support as a family strength and thus was included in that concept. They reported receiving internal and external social support. The families emphasized the importance of emotional supports from the family members above other types of supports. Extended families and health care providers were the most mentioned sources of supports. The type of supports the families received included emotional, instrumental, and informational supports. Figure 8 presents the summary of the findings regarding the family stressors, family strengths, and incorporated family social support as a family strength.

*Figure 8.* Summary of the findings



# CHAPTER 6

# DISCUSSION

The purpose of this study was to identify stressors, strengths, and supports of Thai families who were caring for the persons living with HIV/AIDS. This chapter contains the discussion of the important findings as well as the similarities and differences in the findings between this study and others. First, a general discussion about the sample families is presented, followed by discussion of the family stressors and family strengths. Next, families' needs are discussed, and finally, the limitations, implications, and recommendations for future research are presented.

## Discussion about the Sample Families

### *HIV Affected Families*

HIV disease challenges the traditional definition of family, which includes blood or marriage relationships and a single household. In the HIV/AIDS context, families can be a diverse group whose members can have other relationships. In this study, most families are persons who are related by blood or marriage, however, one PLWA identified friends as his family because he chose not to involve his traditional family due to the stigma of AIDS. It is apparent that families of PLWAs are diverse and extend beyond the traditional family composition. Therefore, the definition of family used in this study was "two or more individuals who depend on one other for emotional, physical, and economical supports". This definition allowed nontraditional families such as a homosexual couple, or a "family" of friends or neighbors to be included in the study. Issues surrounding HIV/AIDS, such as social stigma and multiple losses of family members, make the traditional definition of family inappropriate for studying families who are caring for the PLWAs.

The study incorporates different family compositions such as a married couple, a single mother, a family of siblings, a family of friends, and a two-generation family. These families represent the real world of the HIV/AIDS epidemic in Thailand, where HIV/AIDS affects individuals from all family types. Additionally, the family cases included the informants of different combinations of gender (male and female PLWAs and caregivers), economic status (low to middle income), educational level (less than high school to college), and caregiver relationship (parents, spouses, siblings, and friends). However, there was little variation of the PLWAs' age (adults), stage of the disease (early symptomatic stage), and mode of transmission (heterosexual and homosexual contact). Therefore, the study findings may be different from other HIV/AIDS populations such as children or elderly living with HIV/AIDS; asymptomatic or advanced AIDS individuals, and persons who contacted HIV through blood transfusions or intravenous drug use.

### *Family Caregivers*

It was found that all PLWAs in the study were not abandoned, but willingly cared for by their families. In each family, at least one family member assumed the role of primary caregiver. Very few families had secondary caregivers (family members who assisted the primary caregivers in caring for the PLWAs). The sample of primary caregivers shows a high proportion of female caregivers. This pattern is supported by other studies of HIV/AIDS conducted in Thailand (Jaruwat, 1997; Singhanetra-Renard, Chongsatitmun, & Wibulswasdi. 1996; Songwathana, 1998). This finding is in contrast with the findings in a study of informal caregivers in the United States (Turner, Catania, & Gagnon, 1994) where HIV/AIDS is prevalent among gay communities. That study showed that males were more likely to give care for the PLWAs in central cities, whereas females are more likely to be caregivers within the nation as a whole.

It is noted that, in this study, spouses are more likely to take the caregiver role than other family members. This is because most spouses are more likely to know about the diagnosis and also are victims of HIV/AIDS themselves. However, there were spouses who chose to be caregivers even though they were HIV negative. They attributed their caregiving decision to deep love and close relationships to their spouses.

In this study, all male caregivers were the spouses of the identified patients. Female caregivers were wives of the married patients or mothers of the single patients, except one who was a female friend. Wives or mothers are more likely to be primary caregivers of Thai PLWAs (Chuncharus et al., 1994; Kompayak, 1998; Somnalin, 1997). This is not surprising given the Thai cultural tradition of "a good women", in which she is viewed as a selfless, nurturing female, devoted to her husband and children, and ready to sacrifice for the well-being and good for her family (Klausner, 1997). A sense of deep maternal love also explains the choice to care and the enormous commitment mothers gives to their children living with HIV/AIDS, which was illuminated by the informants' accounts in the study.

## Discussion of Family Stressors

In this study, family stressors were defined as "the problems, conditions, or situations that are capable of causing family instability and threaten family functioning capability and health" (Hanson & Mischke, 1996, p.172). Data illustrated that all families experienced multiple family stressors at the time of interview. There were stressors that were common in daily family life, and stressors that were related to or created by HIV disease. Curran (1985) described 25 common stressors of healthy American families. Stressors identified by Thai families, including children's behavior, economic problems, marital relationship, family' members health/illness, housing problems, career/business/ work situation, and insufficient family time because of overwork, are similar to the common stressors found in Curran's study.

In addition to stressors in the families' daily lives, the HIV/AIDS related stressors challenged the families. The identified HIV/AIDS related stressors could be viewed in the areas of physical (e.g. caregiving tasks, PLWAs' uncertain health status, and planing for impending death), psychological (e.g. PLWAs' emotional suffering, caregiver's burnout), sociological (e.g. discrimination and rejection, concealing the HIV/AIDS diagnosis), and financial (e.g. financial burden).

Some families experienced more stressors than others. The number of family stressors seemed to depend on the families' socioeconomic status. In this study, families with lower socioeconomic status were more likely to have more stressors than families with higher socioeconomic status. For example, families who had insecure financial status were overwhelmed by financial burdens, had difficulties concealing the HIV status, were more vulnerable from employment threats associated with HIV stigma, struggled to seek and receive public assistance, had a limited choice of quality health care services and facilities, and had few or no resources and help in performing caregiving.

The degree of stress created by the stressors also seemed different with each family depending upon the family composition, relationship, and social support resources. Extended families and close-relationship families are more likely to have less stress because they had more inside-family support. Nuclear families tend to perceive more stress because they are more isolated and have less support. Families who have a strong support system from their communities are likely to have less stress.

The degree of stress seemed to change over time. Moreover, some stressors may be more stressful than the others at one point, but vice versa at another point in time depending upon the PLWAs' health status and needs. For example, when the PLWAs were suffering from an illness and/or were in the hospital in critical condition, the PLWAs' uncertain health status and caregiving tasks were the most stressful, whereas discrimination and rejection and concealing the diagnosis were less stressful or important at this time. After the families' financial resources were depleted, the financial burden and struggling with the health care system in obtaining help were the most stressful until the families solved or lessened their financial problem.

Although families identified family stressors together, different family members perceived stressors differently. Particular family members addressed their own stressors: PLWAs mentioned their emotional suffering and caregivers mentioned caregiving task and caregiver's burnout as particularly stressful for them. This reflected that although stressors were viewed as the problems of a whole family as a unit, some individual family members were different in their perception of stressors. This difference should be taken into account when planning for PLWAs and family care.

Despite the differences in culture and health care environments, the majority of family stressors seemed to be consistent across cultures, with slight variation. The study findings demonstrated some family stressors that are unique to Thai families including struggling with the health care system and planning for impending death.

It is important to note that, based on the families' narratives, Thai families seemed more profoundly affected by HIV/AIDS compared to families in the western countries due to several reasons. For example, the availability of advanced treatments, particularly medications, is more limited for most PLWAs in Thailand. Without anti-viral drugs, the disease progresses quickly and Thai PLWAs usually die in a short period of time which makes it difficult for families to cope. Support from HIV related organizations often is not available for those who need it because of the high numbers of PLWAs and limited budget, or the services are not utilized due to ineffective referrals. The hierarchy and power of the health care providers in the Thai physician-dominated health care system becomes a barrier to obtain and negotiate for quality medical care and nursing care.

## Discussion of Particular Family Stressors

There were many stressors identified in this study. However, some common or important stressors are discussed in the following section.

### *Financial Burden*

Financial burden is the first mentioned and most stressful problem for many families living with HIV/AIDS. One reason is that most of the PLWAs were of working age. Another reason is that the patients' conditions required medical treatments for a long period of time and they were currently hospitalized. It is not surprising that they were overwhelmed and struggling with high expenses. Therefore, financial problems were the number one concern at the time of interview. The families, whose members had more progressed disease, or multiple hospitalizations, had more severe financial problems due to more medical attention and hospitalizations.

The initial family income, type of employment, and health insurance seemed to affect how much financial stress was experienced. Low-income families experienced substantial financial strain early in the illness trajectory, because they had few or no financial resources. The financial status of middle-income families was not affected at the beginning, but they experienced financial problems later on, once their financial resources were exhausted. High-income families did not mention financial problems due to HIV/AIDS. Type of employment is another factor that contributed to the families' financial problems. Some families experienced financial strain because wage earners worked in a less flexible job and when they were sick or could not go to work, there was no income. Wage earners who had more flexible jobs such as being self-employed or salaried were more likely to have less financial strain because the PLWAs and caregivers could take time off work without affecting the family's income. Families experienced more financial strain when wage earners lost their jobs or business. Families who had health insurance were more likely to have less financial strain than those who did not until they lost it because of health related-unemployment. The financial burden was more severe when families had no financial support from their social network such as extended families, friends, public organizations, etc.

Financial burdens have been widely reported as the leading problem in other studies of families living with HIV/AIDS (Atkins & Amenta, 1991; Chaiwan, Yachompoo, Kanthamala, 1996; Chuncharus et al., 1994; Chunhapran, Thanasilp, &

Tato, 1992; Phengjard, 2001; Semple et al., 1993). The high cost of medical care, loss of family income, and caregiving related expenses were reported as causes of financial struggling in the study of family caregiving of PLWAs in Thai urban areas (Phengjard, 2001) and in Thai rural areas (Im-aim & Poangsaijai, 1999).

In the present study, the fact that families were facing financial difficulties because of income lost due to having an HIV/AIDS family member was evident by the increasing number of low-income families in the study over time (30% prior to the diagnosis to 70% after the diagnosis). The family income considerably decreased and the family's other financial resources were used in treating and caring for PLWAs. A similar situation was found in the study of Im-aim and Poangsaijai (1999). It is observed that the effect of HIV/AIDS on families' financial status is more severe when wage earners have low or middle income and non-professional jobs with no health insurance or work benefits.

In contrast to the present study, the cost of transportation to health care facilities is not mentioned as contributing to families' financial burden in other studies. This may be because of the location and specialty of the hospital used in this study. Bamrasnaradura hospital is one of the national centers for HIV/AIDS treatments in the central region. Most families in this study were from other areas in the central region. Therefore, a long commute to the hospital was common. The families also relied on more expensive types of transportation, such as taxis or car rentals to commute to the hospital because of the PLWAs' health condition.

Families used various strategies to deal with their financial obligations (e.g. using savings, selling material goods, borrowing money and seeking social welfare). The more advanced the stage of HIV, the more expenses the families had. In the beginning, the families used their own financial resources (e.g. savings, material goods). Once their resources were exhausted, they sought financial resources outside the families (e.g. loans, social welfare). This finding was similar to that reported by Chunhapran and colleagues (1992) and Phengjard (2001). It is evident that Thai families seriously need help with their financial problems as they exhaust their financial resources and go into debt to pay their medical bills. This fact is also reflected by the families' expression of their need for financial support in the present study and others (Chuncharus et al., 1994; Chunhapran et al., 1992; Songwathana, 1998).

### *Struggling With the Health Care System*

Financial burdens also led to another stressor: struggling with the health care system. Frequently, the families struggled to receive health care and social services such as social welfare. This problem is not uncommon in Thailand (Phengjard, 2001). Struggling with the health care system is one of the family stressors that is different from those documented in the Western literature. Often, health care providers, especially physicians, neglect Thai patient's rights or needs. Because of the provider-dominated system in Thailand, patients and families have no power to challenge the power of health care providers. For example, one of the studied PLWA struggled to secure his treatment in the studied hospital and was caught in a conflict between physicians from two hospitals that were involved in his care. It is apparent that power relationships inside the health care delivery system are a primary factor of families' struggles.

Most families are passive and accept whatever they are given by the health care providers and system. To receive what they deserve, often families must be active and defend their rights. Families need to be self-disclosing of their situations/needs and be forthright. Particularly, families have to learn what resources are available and how to actively negotiate for benefits or services. The amount of benefits or services that a family is able to receive from the system depends upon how much that family knows about available services and is able to make the system work for them.

### *Discrimination and Rejection*

Regardless of the studied families' residence, composition, size, or socioeconomic status, all families were subjected to discrimination and rejection from society. However, the wealthy families seem to be able to manage those problems better than the poor families. They can choose to receive care in private health care facilities where their identities will not be exposed; they can afford to employ different strategies to prevent discrimination and rejection such as moving, hiding, or resigning from work when the AIDS appearance presents.

As mentioned, discrimination and rejection are stressful. Discrimination refers to actions or treatments based on stigma and directed toward the stigmatized person (Bunting, 1996). This negative response is a result of the strong social stigma surrounding HIV/AIDS socially constructed in Thai culture (Songwathana, 1998). Not only PLWAs, but also whole families are subjected to discrimination and rejection by society. This phenomenon is confirmed by the Thai literature (Sangchart, Nanthobod, & Ruthjarakarn, 1995; Thampanichawat, 1999) as well as the American literature (Flaskerud, 1995; Powell-Cope & Brown, 1992). PLWAs and their families suffer from the stigma of

HIV/AIDS in the form of social isolation, rejection, harassment, and threats to housing, and employment (Chuncharus, et al., 1994; Phengjard, 2001; Songwathana & Manderson, 1998). Similarly, some PLWAs and caregivers in this study felt that having HIV would jeopardize their employment, careers, and businesses, as well as residences.

Stigma is a mark of shame and discredit (Bunting, 1996). Although AIDS stigma exists in both Thai (Pornsiripong, 1994; Songwathana, 1998) and western culture (McCain & Gramling, 1992; Powell-Cope & Brown, 1992; Semple, et al., 1993), the cause of stigma differs. While AIDS related stigma in western countries is related to the prejudice against homosexual behaviors and IV drug use (Alonzo & Reynold, 1995), this stigma in Thailand is more related to the fear of contagion, promiscuous behaviors, and visiting or being prostitutes (Songwathana, 1998). AIDS related stigma in Thai culture was originally constructed by the government's prevention campaigns using media's description of HIV/AIDS. Unfortunately, these campaigns provoked pervasive fear of the disease and defined characteristics of people who were marked by their deviant actions (e.g. prostitution, drug use) as threats of HIV infection (Lyttleton, 1996; Songwathana & Manderson, 1998; Treemulca, 1996). These campaigns influenced how communities react to PLWAs. Without exception, families in this study were affected by the negative societal perceptions of PLWAs. The families shared their experiences of isolation where people would avoid socializing with them—not get too close, visit, do business or work with them, or be present in the same location—which are similar to what Pornsiripong (1994) reported in her study. In Thailand, a unique characteristic of HIV/AIDS that is associated with stigma is the fact that it is transmitted sexually, so the cultural perception is that HIV/AIDS is a "disease of karma" (Songwathana & Manderson, 1998). The studied families repeatedly mentioned that bad karma was created by the PLWAs' sinful acts. In this sense, the PLWA deserves to die or suffer from HIV/AIDS because they have brought it on themselves. Other studies (Phengjard, 2001; Singhanetra-Renard, et al., 1996) have suggested that the stigma of HIV/AIDS is constructed by societal views of HIV/AIDS as dirty (as is related to prostitutes), disgraceful, contagious, and deadly. It is also associated with unacceptable behaviors such as promiscuity, drug use, and homosexuality. This present study showed that, as a result of these perceptions, people have feelings of disgust and disdain, and avoid getting close to or socializing with PLWAs and their families.

### *Concealing the HIV/AID Diagnosis*

The studied families described their efforts to conceal the HIV/AIDS diagnosis as stressful. Concealment of a HIV diagnosis reflects the negative image of HIV/AIDS held in Thai communities. Fear of stigmatization, discrimination and rejection from society forced the studied families to keep the HIV status hidden. Therefore, when it was unavoidable, families carefully selected individuals to whom they reveal their secret. The individuals to whom the diagnosis was revealed were ones who had close relationships with the families, could provide help with the caregiving, were believed not to have negative responses such as shunning, disgust, discrimination, or rejection, or were believed not to reveal their secret. This phenomenon is consistent with what had been found in other studies (Phengjard, 2001; Powell-Cope & Brown, 1992; Serovich, et al., 1992; Thampanichawat, 1999). These efforts to conceal may help explain this study's finding that families receive limited informal support from friends, neighbors, and co-workers; and/or prefer to have formal support from health care professionals. Since Thai society in general holds superficial and inaccurate perceptions about HIV/AIDS, friends, neighbors, and co-workers are not considered by families to be safe holders of their truths about their disease. In contrast, families are more comfortable revealing their diagnosis to health care professionals, believing that they can trust them to keep their secret, and assuming that they will not be discriminated against because the health care providers have better knowledge and understanding about HIV/AIDS. In an effort to avoid discrimination and rejection, the studied families misled others to believe that the PLWAs were sick with other non-stigmatized diseases. The misleading helped the families receive support normally given by communities to families with other diseases, but not with HIV disease. Songwathana (1998) found another reason to conceal HIV status in her study of families in Southern Thailand: contracting HIV virus brought shame to the families and destroyed the reputation of whole family as well as the individual members. However, the families in this present study did not mention this reason. This may be due to geographical differences.

Concealing their family member's HIV status results in a lack of social support for the affected families. Even though the PLWAs and their families have a greater need for support, they feel vulnerable to discrimination and find it is difficult to acquire support. Fear of rejection leads to a reluctance to ask for support from outside the family and isolation and withdrawal from social relationships. Based on the findings, it is apparent that having a family member living with HIV/AIDS alters the network structure that families normally would have if they had another disease. This finding is supported by the findings of another study in which the PLWAs and families had fewer social networks than the patient and family who had other diseases (Atkin & Amenta, 1991).

### *Caregiver's Burnout*

Caregiving was pointed out as stressful and overwhelming for the families who are providing care to their members living with HIV/AIDS. It is noted that caregivers who have no help or support from other family members are more likely to report burnout from caregiving. Pearlin, Aneshensel, and Leblance (1997) documented that caregivers' stress involved the hardships rooted in the caregiver role. Brown (1993) also confirmed that caregiving demands were extensive, as the caregivers performed their tasks, including mental, physical, and emotional management, to meet the PLWAs' needs on a daily basis. Caregiving demands and tasks performed vary depending upon the illness trajectory and phase of caregiving (Brown, 1997). The more advanced the illness, the greater the demands of caregiving. The present study had similar findings regarding extensive demands of caregiving tasks, but did not reveal a change in the amount of caregiving demands over time because the data were not collected from families across the illness trajectory. The demanding nature of caregiving leads to caregivers' emotional and physical burnout. The caregivers' accounts reflected their experiences of burnout both physically and emotionally. Similar experiences had been reported in the works of Brown (1993), Flaskerud and Tabora (1998), and Turner, et al. (1994).

Fear of contagion while caregiving is common among family members living with the PLWAs (Flaskerud, 1995; Giacquinta, 1989). Although, the studied families did not specifically mention fear of contagion as a stressor, the caregivers expressed their fear of unintentional exposure when performing the caregiving tasks. Caregivers indicated that preventing the spread of infection was stressful. Interestingly, although they acknowledged that it is important to protect themselves from exposure, some families were not be able or chose not to do so. The primary reason was that they could not afford protective and disinfecting supplies. Other reasons were a desire not to hurt the PLWA's feelings and efforts to prevent suspicion about HIV. These failed practices stem from the issues surrounding HIV/AIDS in Thailand, such as financial problems, and strong AIDS-related stigma.

The studied caregivers who had provided intensive caregiving for a period of time experienced negative effects on their health such as fatigue, sleep deprivation, weight and appetite loss, and changes in pre-existing health problems. Caregivers that were elderly parents had more health problems caused by performing care than other caregivers. These effects on physical health are consistent with what has been reported in other studies (Turner, Pearlin, Mullan, 1998). This finding demonstrates health care providers need to focus on helping caregivers to maintain their health physically and emotionally in order to be able to continue providing care to the PLWAs. Brown and Powell-Cope (1991) described the caregiver's perception as "being managed by the illness" and "never being able to do enough" to obtain positive results in their caregiving. The studied families did not have a similar perception of being managed by the illness, but they shared similar feelings of frustration and helplessness regarding their inability to provide a level of care that would help maintain the PLWA's health.

### *Caregiving Tasks*

Families were stressed when performing caregiving tasks to meet the PLWAs' needs. The reasons are that families have insufficient knowledge, skills, and inadequate tools and supplies to perform caregiving tasks. Caring for the PLWA requires education, skill, and community resources (Flaskerud, 1995), as well as adequate tools and supplies to perform the functions of caregiving (Phengjard, 2001). With little knowledge and skills, families feel a lack of confidence in performing caregiving tasks. The majority of families in this study managed their caregiving by themselves without help or support from their communities. Providing care without enough knowledge, skills, supplies and appropriate tools seems to diminish their ability to perform quality caregiving. Similar circumstances were described in other studies of Thai caregivers (Chuncharus, et al., 1994; Chunhapran, et al., 1992; Im-aim & Poangsaijai, 1999).

### *PLWA's Uncertain Health Status*

In the present study, HIV/AIDS brought much uncertainty into the lives of the affected families, and caregivers in particular. A grounded theory study described caregivers' experience of uncertainty as the inability to predict future events and outcomes of caregiving (Brown & Powell-Cope, 1991). The study suggested that uncertainty in AIDS family caregiving arises from the perpetual and unpredictable changes accompanying AIDS. Brown and Powell-Cope's (1991), and Nilmanat's (1995) findings of uncertainty, are comparable to the stressor identified by the family samples: PLWAs' uncertain health status. It was found that uncertainty was particularly pronounced when new opportunistic infections developed and during periods of hospitalization. The families felt that they could not predict nor do anything to control what might happen to the PLWAs, especially their death.

### *PLWAs' Emotional Suffering*

PLWAs' emotional suffering is caused by the negative image of HIV/AIDS. The accounts of the PLWAs reflected their feelings of guilt, shame and sinfulness of contracting HIV/AIDS and infecting other family members, hastening their death. These feelings are common among the PLWAs and can create high stress and anxiety, which lead to psychological distress, depression, and even suicide (Flaskerud, 1995). To date, health care services focus primarily on physical care and, in most cases, overlook the PLWAs' emotional well-being. Patient care currently does not integrate psychological care, especially suicide prevention, into AIDS treatment. Although it is necessary, counseling services for the PLWAs and their families are scarce, particularly in small or private health care facilities.

### *Planning for Impending Death*

Planning for impending death is another stressor specific to families in Thailand. Planning means preparing what to do when the PLWAs are in the terminal stage of their illness and what to do after their death. Since HIV/AIDS is associated with such a strong social stigma, it is necessary to prepare for taking care of terminally ill family members and, at the same time, protect them, and the families, from social discrimination. For the studied families, this preparation required much effort and was sometime stressful. Decisions were made ranging from housing or a place to die; to who will raise the children; to what, when, and how much information would be revealed about the death of the PLWAs; to arranging for a private funeral ceremony. In Thailand, there are concerns about the safety and well being of the family members who are left behind. Learning from the experiences of other families living with HIV/AIDS, families realize that they will suffer long-term negative effects, even after the death of the PLWAs. Often, communities shun families after it is disclosed that a family member died of AIDS. Thus, families feel the need to prevent or deal with possible discrimination, rejection, threats, and harassment from their communities.

## Discussion of Family Strengths

In this study, family strengths were defined as “the abilities and resources, which are used by families to solve problems and cope with stressors” (Hanson & Mischke, 1996, p. 179). The study findings revealed that, when the families encountered stressors, they were able to mobilize their abilities and resources to cope with the stressors in order to maintain the family’s functions and system stability. It is apparent that the family sample employed several strengths while dealing with HIV/AIDS related stressors. Some families mobilized more strengths than others; however, there is no relationship between the family’s characteristics and the number of strengths they reported.

The study results show that some strengths come from a family’s values and previous experiences dealing with problems in life, while some are strengths that emerge over the course of the illness. For instance, family strengths such as religious faith, sense of forgiving, and family obligation originate from the values the families share, whereas, receiving social support and working together come from previous experiences in coping with other stressful situations. Family strengths, including maintaining hope, emotional connection, diverting attention from HIV/AIDS, and focusing on the present, are developed over the course of the illness to cope with the stressors related to HIV/AIDS.

Although the families in this study shared some strengths, such as religious beliefs and experiences working together as family, family members employed particular strengths that they felt were the most helpful to them. For example, family caregivers build their strength based on a strong sense of family obligation. Spouses draw strength from a sense of forgiveness and understanding. PLWAs find that receiving social support, diverting attention, focusing on the present, and maintaining hope strengthen them.

Particular strengths arise out of other strengths the families possess. Strengths such as the family working together and a sense of forgiveness and understanding lead to another strength: strong emotional connections between family members. Buddhist beliefs foster families' strengths, including maintaining hope and having a sense of forgiveness.

All family strengths found in this study are similar to what have been found in the western literature with the exception of one: a strong sense of family obligation. Western literature documents that family obligation to care for the PLWAs often relates to stress and leads to burdens on families (Brown & Powell-Cope, 1991; Brown & Powell-Cope, 1993, Folkman, Chesney, & Christopher-Richards, 1994; Pearlin, Semple, Turner, 1998). However, for Thai families in this study, a sense of family obligation was considered a family strength because it inspired them to provide care for their sick members. This may be explained by the cultural difference in the meaning of family obligation to care for the PLWAs. The Thai cultural value is that a family has primary and natural responsibilities for the care of their sick members; thus, caregiving is viewed as the family's business (Phengjard, 2001). Grounded in this cultural value, families naturally accept such responsibilities without questioning their choice or feeling that they are being forced to care for their sick members.

As stated in the literature review, most research studied coping strategies families use when facing stressful situations related to HIV/AIDS instead of studying about family strengths (Aranda-Naranjo, 1993; McCain & Gramling, 1992; Powell-Cope & Brown, 1992). Most family strengths reported in this study are comparable to coping strategies reported in those research studies. These included turning to religious beliefs (Hall, 1994), seeking and receiving social support (McCain & Gramling, 1992; Powell-Cope & Brown, 1992; Stewart, Hart, & Mann, 1995), maintaining hope (Hall, 1994), focusing on the present (McCain & Gramling, 1992), and diverting attention from HIV/AIDS (McCain & Gramling, 1992; Pearlin, et al., 1998). When compared to Curran's (1983) study of family strengths in healthy American families, only a few similarities to Thai families living with HIV/AIDS (e.g. religious beliefs, social supports) can be found. Discrepancies in family strengths may be explained by the fact that the studied families were dealing with stressors related to fatal illness in a family member, whereas the families in Curran's study were not dealing with illness related stressors. Also, different family/cultural values constitute a possible explanation for the dissimilarity of strengths between the families in the two studies.

## Discussion of Particular Family Strengths

### *Religious Beliefs*

All families in this study were Buddhists. Since Buddhist philosophy has a strong influence on the lives of Thai people, it becomes a family resource when dealing with the stressful events that surrounded those living with HIV/AIDS. The studied families indicated that religious beliefs were the most helpful in dealing with the suffering created by HIV/AIDS, and confronting the impending death of their loved ones. Several studies (Hall, 1994; Songwathana, 1998; Tansriratanawong, 1998) have supported the important role of Buddhism in coping with HIV/AIDS. Tansriratanawong (1998) found that the PLWAs used Buddhist teachings as a way of spiritual healing. Songwathana (1998) provided evidence that Buddhist belief in karma as well as death as a normal process of human life, provide explanations for contacting, living with, and dying of AIDS. The role of religious beliefs in coping with HIV/AIDS was also reported in the western study (Hall, 1994). Hall founded that religious beliefs provide a framework for coping with the death of PLWAs.

*Receiving Social Support*

This study began with exploring family social support as an individual concept of interest, because social support was viewed as having an influence on the effects of stress on the family systems. In the conceptual model, family strengths and family social support were conceptualized as the two components of a family's defense system that promoted adaptation to the stressors. However, it is interesting that the study results showed that families identified receiving social support as one their strengths. It is possible that families utilized the received social support as a resource to solve problems and cope with stressors. Having social support has, in fact, enabled families to effectively cope with their stressful situations (Pearlin, et al., 1998). The work of Curran (1983) regarding strengths of American families confirms this finding. Curran's investigation identified family affirmation and support as a family strength.

In this study, family social support was defined as "a process of relationship between a family and its social environment" (Kane, 1988). Kane described the relationship between the family and its social network as comprised of a flow of energy in terms of information, goods, services, and emotions as family social support. In the present study, it was found that some families had relationships with various persons in their social networks, and these people interacted with the family in ways that provided various forms of social support. Two components of social support, family social networks (sources of support) and type of social support, were examined in this study. The discussion of each component follows.

Based on the study results, families receive different types of support from different sources. Particular social support is helpful when provided by particular sources. The nature of HIV disease and its uncertainty initiate social support in the form of informational and instrumental support from health care providers; while the demanding caregiving initiated both instrumental and emotional support from family members and extended families.

The findings show that family members and extended families were the significant sources of support. This finding is comparable to those described in other studies (Chunchaurs, et al., 1994; Chunhapran, et al., 1992; Huntragool, 1992; Phengjard; 2001). Because of fear of exposing the HIV status, the families distance themselves from their community and have to rely on each other within the family and extended family for support. In Thai culture, support from extended family members is commonly expected when a member is sick. However, for some families in this study, the support from the extended families was limited due to their abilities (poverty, poor health) and geographical distances that prevented them from lending support.

Besides extended family, the studied families identified few social network members who provided support. Sporadically, friends, neighbors, and co-workers were the sources of support. This may be due to the strong social stigma in the communities and workplaces, and the lack of laws to prevent discrimination or threats against PLWAs at work.

To avoid discrimination and rejection, families living with HIV/AIDS are more likely to rely on formal sources of support, such as health care providers and HIV/AIDS organization, rather than a network of friends, neighbors, and co-workers. They feel that their secret will be safe, and believe that they will be treated with respect and sensitivity, because health care providers are professionals who have a better knowledge and understanding about AIDS than lay people. It is observed that there was no mention of nurses as a source of support. It is also possible that there is a shortage of nurses in the studied hospital units and clinics and they are overwhelmed by the patients' bedside care, so they do not have time to provide support for the patients and their families. This finding suggests the need to increase the nurse's role in providing support for the PLWAs and their families.

Among various types of support, emotional support is the most valued and desired by the families (Chunhapran, et al., 1992). Giving encouragement with kind words was considered invaluable to the PLWAs to help them overcome their suffering and give them strength to live (Phengjard, 2001). This study's finding concurs with those of Phengjard (2001) and Chunhapran, et al. (1992). It was found that emotional support, including encouragement, is the most needed and most important type of support for people living with HIV/AIDS and their families. Other studies similarly addressed the strong importance of family emotional support (Hudson & Morris, 1994; Stewart, et al., 1995).

Although social support was identified as a family strength for some families, other families did not receive the social support they needed. Being fearful of rejection, some families isolated themselves from their social network, resulting in limited social support. Limited social support found in this study is similar to those found by other researchers (Chunhapran, et al., 1992; Hudson & Morris, 1994; Phengjard, 2001; Sangchart, 1997; Smith & Rapkin, 1996). It is noted that Thai families did not mention a lack of social support as a stressor like the western families (Andrews, 1995; Semple, et al., 1993; Takigiku, et al., 1993). This may be a reflection of the Thai cultural belief. Thai people believe in an individual's effort to solve his or her own problem, with no expectation of supports from society (Podhisita, 1998). Another reason may be that the families choose to keep their HIV status secret and willingly accept the consequence of that act, which is to receive less or no support.

### *A Sense of Forgiveness and Understanding*

A sense of forgiveness and understanding is a family strength that plays an important role in the family's willingness to care for a PLWAs. All male spouses living with HIV/AIDS in this study contracted HIV through heterosexual relationships with prostitutes before and/or after marriage. Because of the sexual double standard of pre-marital and extra-marital sexual promiscuity for men in the Thai culture (Klausner, 1997), female spouses in this study expressed their senses of understanding and forgiveness for their husbands' unfaithful acts. They chose to stay in their marriages and provide care to their husbands. Feeling of guilt for bringing the HIV virus to his wife, as well as emotional connections between them, are sources of forgiveness for the husband (Phengjard, 2001).

### *A Sense of Family Obligation*

The family, in which women play roles as caregivers, is responsible for providing care for sick members and elderly people in traditional Thai society (Kanungsukkasem, 1993; Yoddumnern-Attig & Attig, 1993). The conventional norm of family obligation is strong in the Thai culture, but is challenged by the social stigma attached to HIV/AIDS. Families' panic about possible contamination or fear of discrimination and rejection can lead to unwillingness to care for the PLWAs. However, that was not the case in this study where all families provided care for their HIV infected members. The willingness to care for the PLWAs may be influenced by a feeling of competency to care for the PLWAs, or because of family strengths such as emotional connection, sense of understanding and forgiveness, and particularly a strong sense of family obligation. The families viewed their care as the family's natural duty or responsibility. A strong sense of obligation inspires the families to overcome the fear of contamination, discrimination, and rejection by accepting and caring for the PLWAs. Although, caring for the member living with HIV/AIDS involved burden and stress, the families' accounts did not reflect resentment or complaint about the decision to care for the PLWAs. There seems to be an implicit sense of doing the right thing, as a family should do (Muecke, 2001). In this study, the families described as their strength the ability to maintain a sense of obligation, against the mainstream of families who are neglecting their family members living with HIV/AIDS. The similar perception of family obligation was also found in other studies of Thai families (Phengjard, 2001; Muecke, 2001).

### *Maintaining Hope*

The families living with HIV/AIDS in this study continuously coped with the stress of uncertainty and impending death. One strategy they use is to maintain hope for prolonged lives and a cure for AIDS. Hope plays an important part in helping the families continue to live, and do what they need to do, while living with HIV/AIDS. The importance of maintaining positive attitudes, such as hope, has been reported in other studies (Allan, 1990; Hall, 1994; Pearlin, et al., 1998; Tansriratanawong, 1998). Motacha (1998) noted that the caregiver draws on this strength in order to sustain optimism and hope, and to be able to live one day at a time. Allan (1990) found that the participants developed positive attitudes such as focusing on living, not dying, and being optimistic and hopeful. Some reported that their beliefs in miracles kept them hopeful. Hall (1994) also described hoping for a miracle as one of four ways that hope is maintained in persons living with end-stage HIV.

Other family strengths identified in this study are similar to what have been reported in other studies, including family's' working together (Chuncharus, et al., 1994), focusing on the present (Pearlin, et al., 1998), diverting attention from HIV/AIDS (Pearlin, et al., 1998; Stewart, et al., 1995), and maintaining emotional connection (Juthavijit, 1990).

## Relationships Between Family Stressors and Strengths

When challenged by stressors, families employed strengths to help them deal with stress. There is no relationship between the number of stressors and the number of strengths the families experienced in this study. However, it is noticed that families who reported more strengths also perceived less stress, regardless of how many stressors they had. The studied families addressed the impacts of strengths, such as turning to religious beliefs, receiving social support, and maintaining hope, in a way that indicated their belief that these strengths helped decrease stress. Using a case study design, this study did not intend to verify the mediating effects of strengths on the stress levels. However, the findings suggest that the strengths appear to have a positive influence on a family's experiences of stress. For instance, families found comfort in their faith when they were suffering from stress. Receiving social support provides strength or resources to mediate stress. When the burnout from caregiving occurs, receiving emotional support can be uplifting and sustaining. Additionally, receiving instrumental support in taking care of the PLWAs can reduce some of the caregivers' burden and stress. Families' strong sense of obligation and willingness to care for the PLWAs can alleviate the PLWAs' stress involving guilt and feelings of being a burden to their families. Maintaining hope can lessen stress and strengthen the families in dealing with the uncertainty of HIV/AIDS.

## Discussion of Families' Needs

The findings show that Thai families living with HIV/AIDS have particular needs in the areas of support services, including counseling, support groups, HIV/AIDS education, financial assistance, and caregiving support such as home care. These needs are related to stressors the families encountered. The need for financial assistance is extremely great as families' struggle to pay high medical expenses. Similarly, caregiving support, both instrumentally and emotionally, is needed because of demanding and complex caregiving tasks and feelings of burnout. Stress generated by fear of discrimination, rejection, and impending death of the loved one, leads to the need for psychological care, such as counseling and group support services.

These families' needs reflect problems in the Thai health care system in that the families do not have adequate access to the resources they need. Even though, in Thailand, those services and supports are available at the present time, they are not well established in a way that allows equal and easy accessibility. Also, in some places, such resources are limited. Families who do not know how to access and actively search for services seemed to lose their opportunity to get them. Referral systems should be improved to allow more access to the services and resources families need. Need assessments by health care providers should be performed to evaluate each family's needs. Health care professionals should facilitate and advocate the effective use of services and resources. Families emphasized their need for caregiving support at home, especially when the PLWAs are in the advanced stage of their illness. This reflects the lack of effective community health care in the Thai health care system, particularly in urban areas.

## Limitations of the Study

The PLWAs in this study were in an early symptomatic stage of HIV. Thus, experiences were limited to this stage of illness. These findings may not represent the stressors and strengths of families in early asymptomatic or the later stages of HIV disease, we know the demand and course of this illness changes over time. Family stressors and strengths may differ at different stages of their HIV/AIDS illness trajectory. Informants from all stages of HIV disease should be included in further study or the sample families should be followed through the complete course of their illness, as well as after the PLWA's death. This study did not recruit families from early stages of HIV because data were collected in the hospital's inpatient unit where patients were in their symptomatic stage. Additionally, this study was not able to follow families longitudinally because of time constraints. Therefore, the findings do not provide the complete picture of families living with HIV/AIDS.

The study sample was limited to families with low to middle socioeconomic status in an urban area. The study results may not be transferable to those with higher socioeconomic status or those in rural areas, as the stressors and strengths may vary due to socioeconomic advantages and demographic disadvantages. Additionally, the study's results only represent the experiences of the PLWAs and families who received a medical care. The experiences of those who do not receive a medical care may differ from what have been found in this study.

## Implications of the Study's Findings

This study is one of a few studies in Thailand to explore families' experiences of caring for members living with HIV/AIDS from the family's perspective. The study's results contribute to better understanding of the phenomenon of families caring for the PLWAs in Thailand. In addition, this study is one of a few studies in Thailand that has used the family as a unit of analysis where data were collected from all family members. This study demonstrates that various perspectives of family members provide a broader picture of the family system and better represent the experiences of the families.

The family of a PLWA is not commonly included as a primary target of health care services or interventions in Thailand. The major contribution of this study is that it offers health care professionals a better understanding and insight into the lives of not only the PLWAs, but also families caring for their sick members in Thailand. Knowledge gained about family stressors and strengths could help inform and draw the attention of health care policy makers, who are typically patient-focused. It will assist them in being more aware of the problems and needs of families living with HIV/AIDS, and encourage them to improve health care delivery according to the information learned in this study.

The study results may guide nursing care programs or services that aim to help reduce stressors and foster strengths in families living with HIV/AIDS. Knowledge about stressors could be helpful to the provision of counseling and support group programs for families. Intervention programs can be developed based on the information in this study to provide the support the families need, as well as to help the families draw upon their abilities and resources to effectively cope with the stressors. For example, a support group and counseling program for the caregivers and family members would allow families to be listened to and to share their experiences, as well as to learn about each other's experiences. A counselor can encourage the PLWAs and their families to use Buddhist philosophy and practices for comfort and for coping with their feelings about the death of their loved one. The findings also suggest that families need an educational program that provides information about HIV disease and caregiving.

The study results could be useful in designing home care or hospice care programs that continue to offer instrumental, informational, and emotional support to the families at home, after the PLWAs are discharged from the hospitals. Families' experiences of struggling with the health care system and social services may prompt the health care community to examine and improve the system to better serve this population. In sum, families living with HIV/AIDS have unique challenges that differ from other diseases. The knowledge generated from this study suggests that there is a need for effective health care services and interventions that are specifically designed to meet the identified needs, stressors, or problems of this population.

## Recommendations for Future Research

It is noteworthy that the broader family definition used in this study is appropriate and recommended for use in future research on HIV/AIDS families. Using this definition assured that non-traditional families, such as homosexual couple or friends would not be excluded from the study.

Families' experiences are dynamic due to the roller coaster nature of the AIDS disease trajectory; family stressors and strengths may change along this trajectory. Further research should explore stressors and strengths in all stages of HIV/AIDS, by following up on the families from first diagnosis through death. Such a longitudinal study would be beneficial in providing a complete picture of families living with HIV/AIDS. In addition to the inclusion of informants from all stages, prolonged engagement in data collection and individual interviews of each family member would provide more in-depth information about the family as a whole, as well as about individual members who play different roles. Participant observation may be included in the data collection method. Comprehensiveness and validity of the data may be enhanced if the family's activities and behaviors are observed.

Building upon the findings of this study, future research should be aimed at exploring stressors and strengths of specific types of families-- for example, families of HIV infected pregnant women, families of HIV infected children, families of grandparents and HIV infected grandchildren, homosexual families, and families who have lost their loved ones from HIV/AIDS-- in order to find out whether different types of families have different specific stressors and strengths. Future research may further explore the experience of stressors and strengths of caregivers, especially spouse caregivers as they face multiple challenges of HIV/AIDS caregiving, family caretaking, and also the stress of being AIDS patients themselves.

The last recommendation involves the interview process. Researchers should be prepared for intense emotional reactions when interviewing informants. Feelings of guilt for bringing up sad and stressful memories or experiences, or for intruding upon the time and energy of families who are already dealing with enormous stresses are likely to arise. The informal or formal support of others will be helpful for researchers.

## Summary

Findings developed through this qualitative study added to the body of knowledge about family stressors and strengths when caring for a family member living with HIV/AIDS. The experiences of stressors and strengths from ten families were explored through a case study design. The knowledge gained provides useful information for health care providers and policy makers to better enable them to customize health care services to help Thai families live with HIV/AIDS, and to better meet their needs. Limitations of the study findings and recommendations for future research were derived from the findings of this study.

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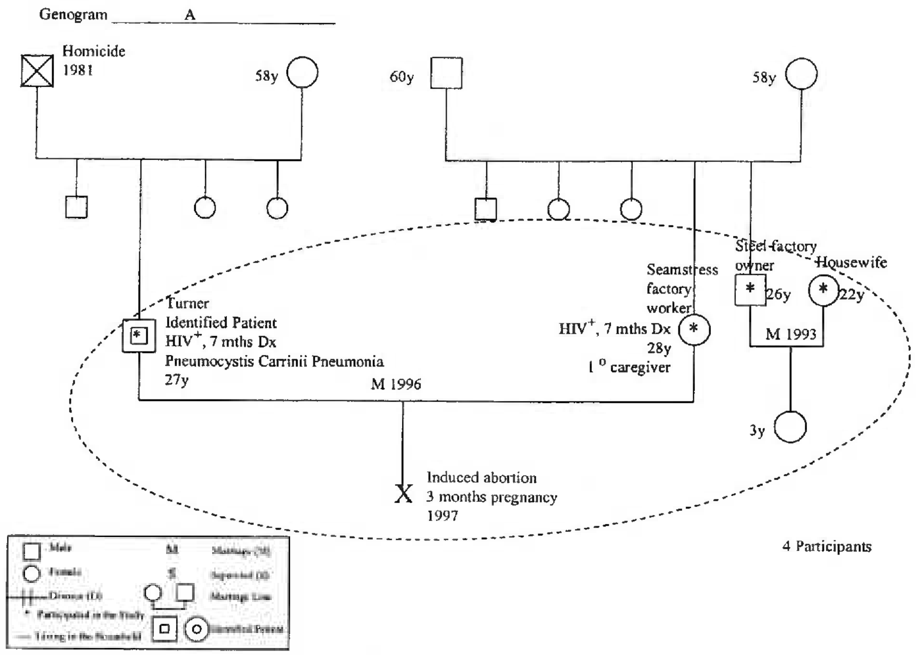
# Appendix A

## Genograms and Ecomaps of the Family A through Family J

# GENOGRAM



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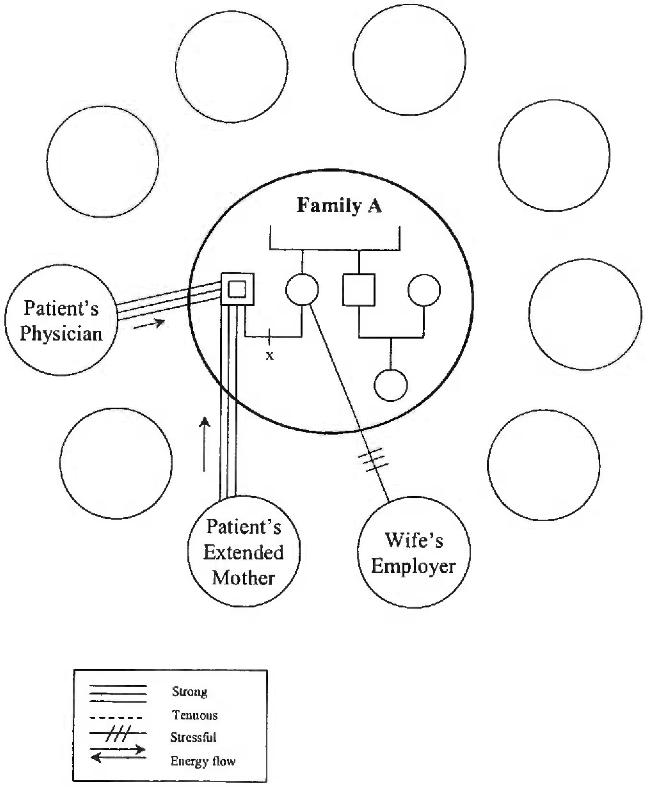
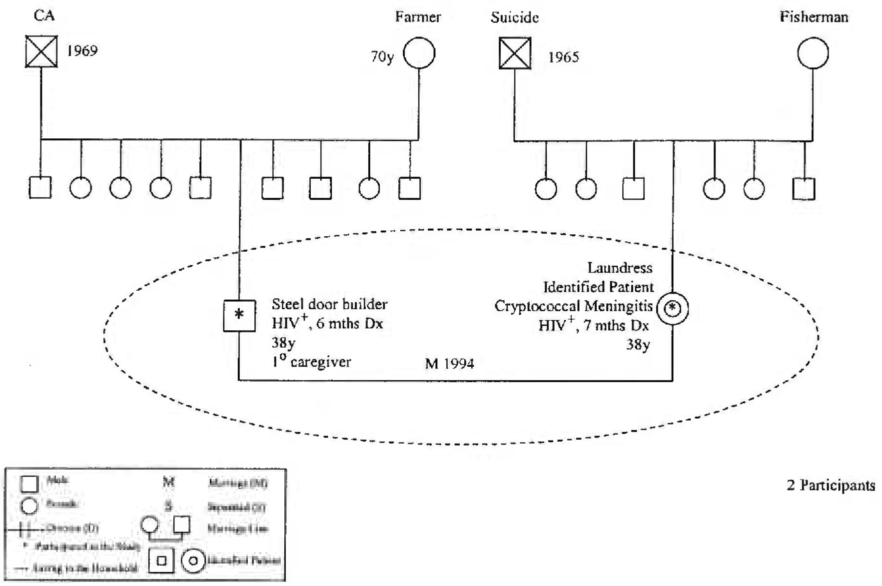


# GENOGRAM

Genogram ________B________________



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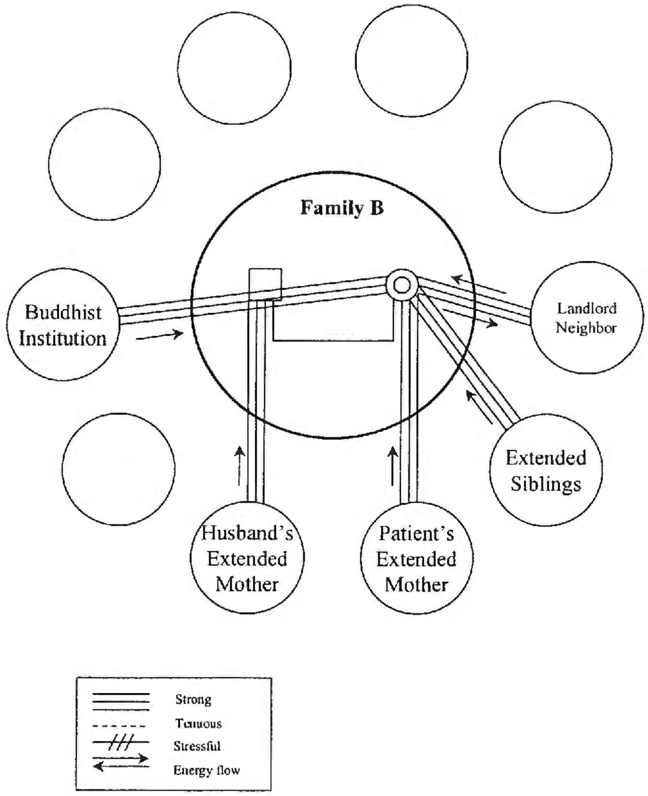

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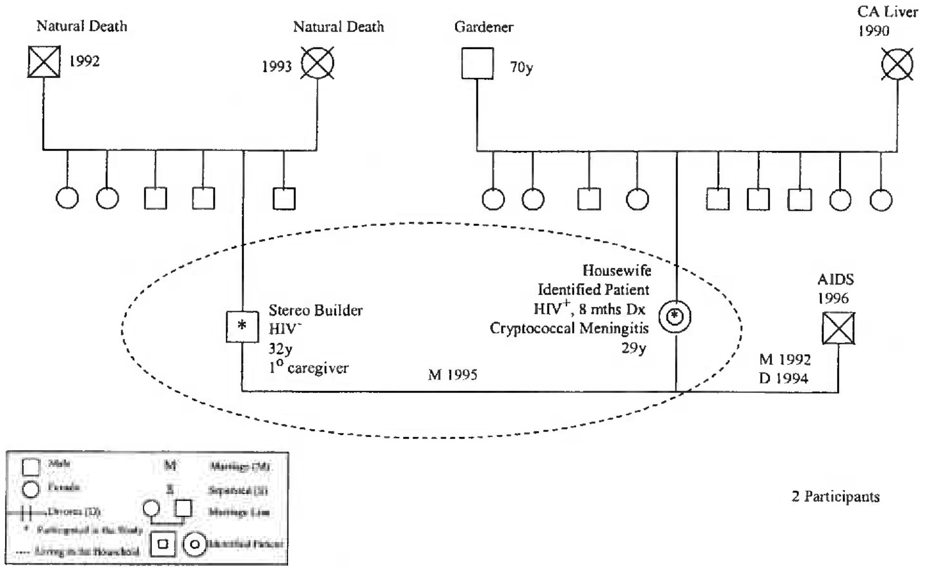

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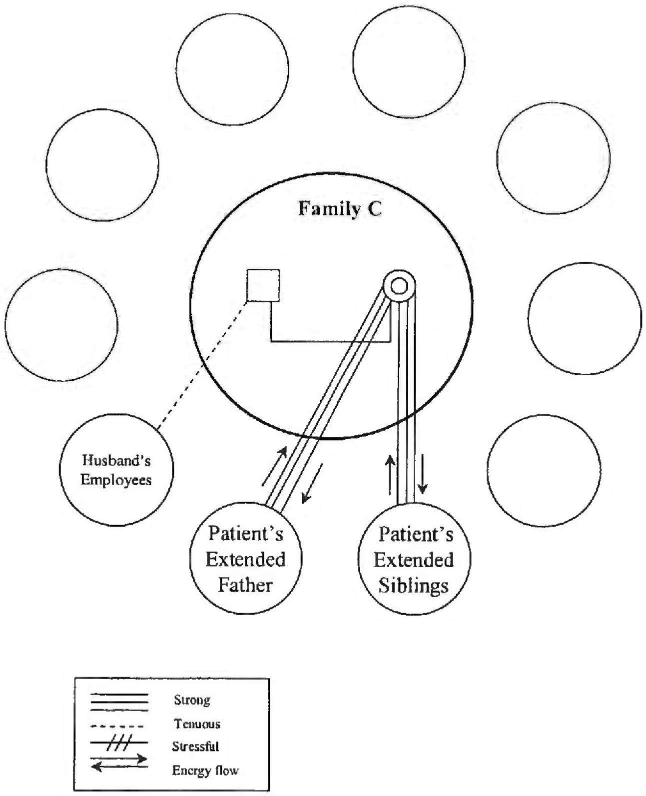

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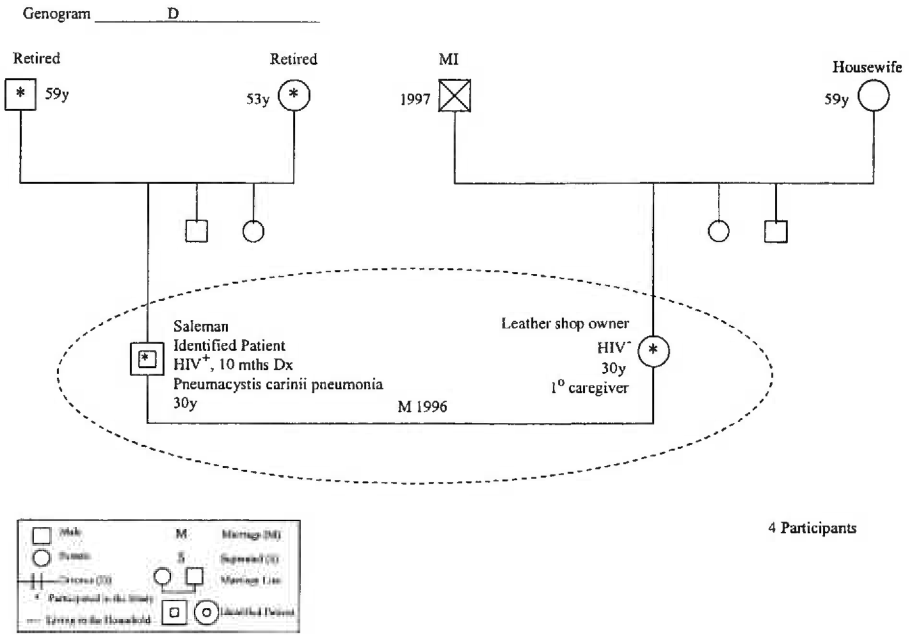

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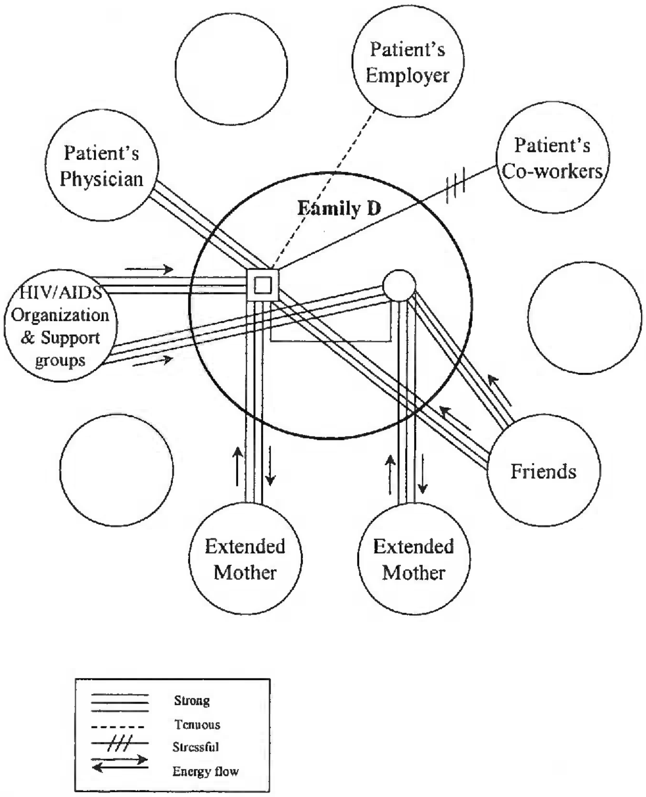

# GENOGRAM

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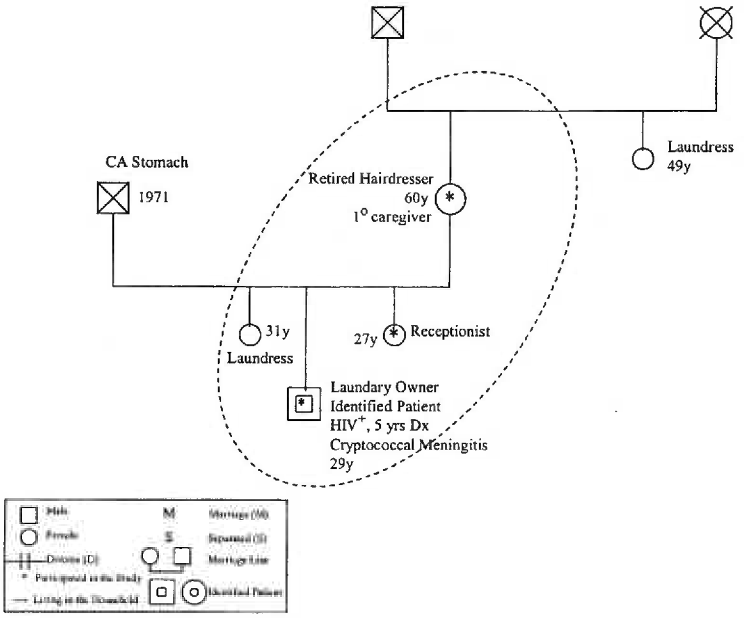
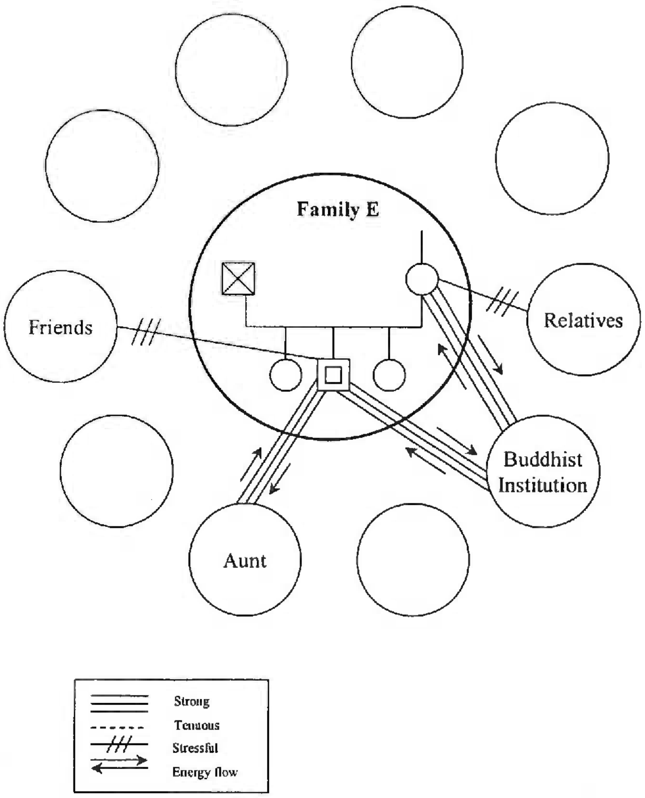


3 Participants

# ECOMAP



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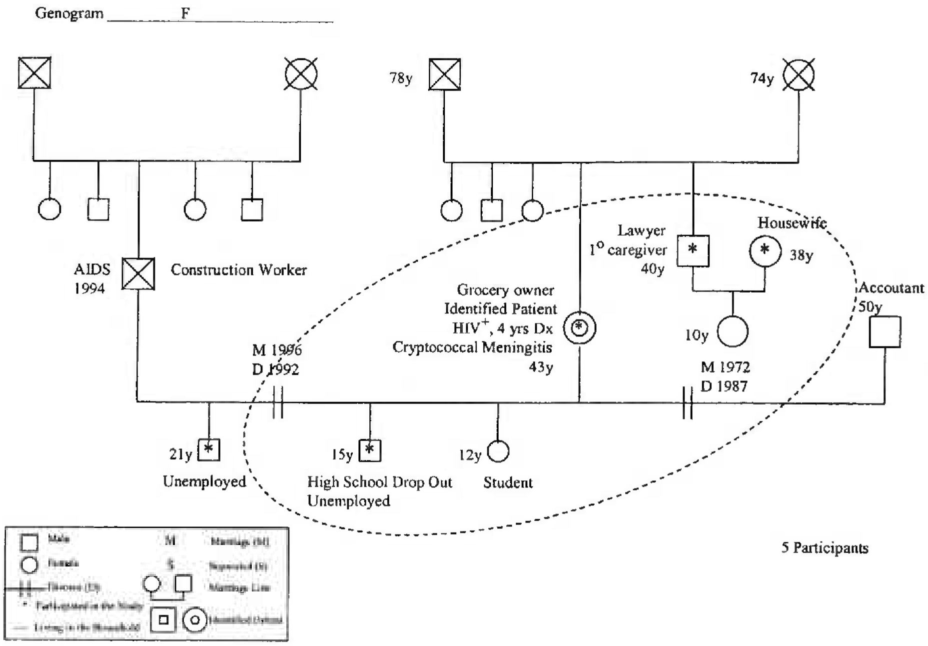

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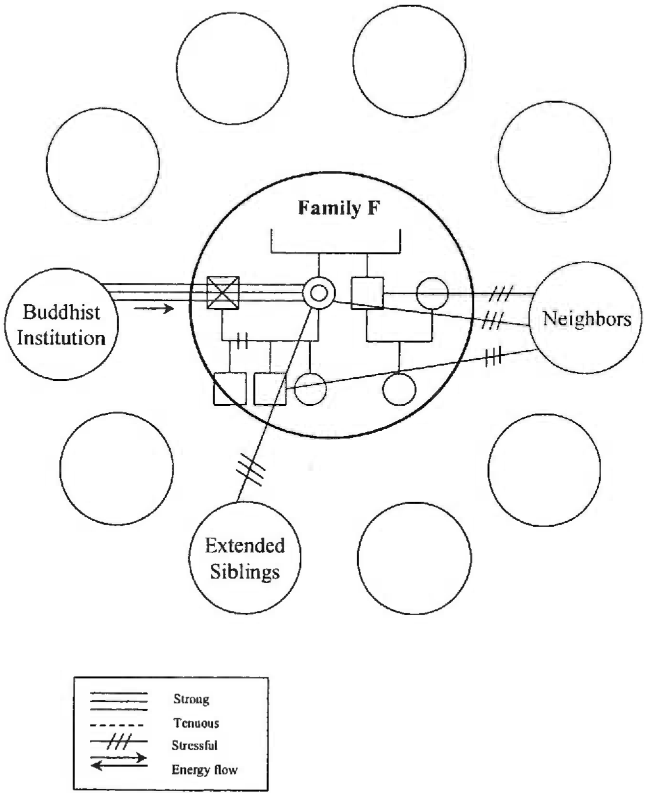

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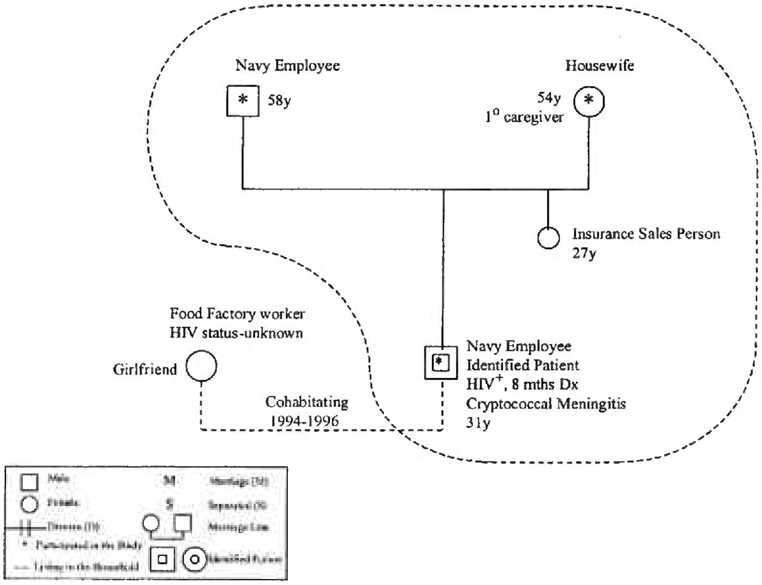
Genogram G



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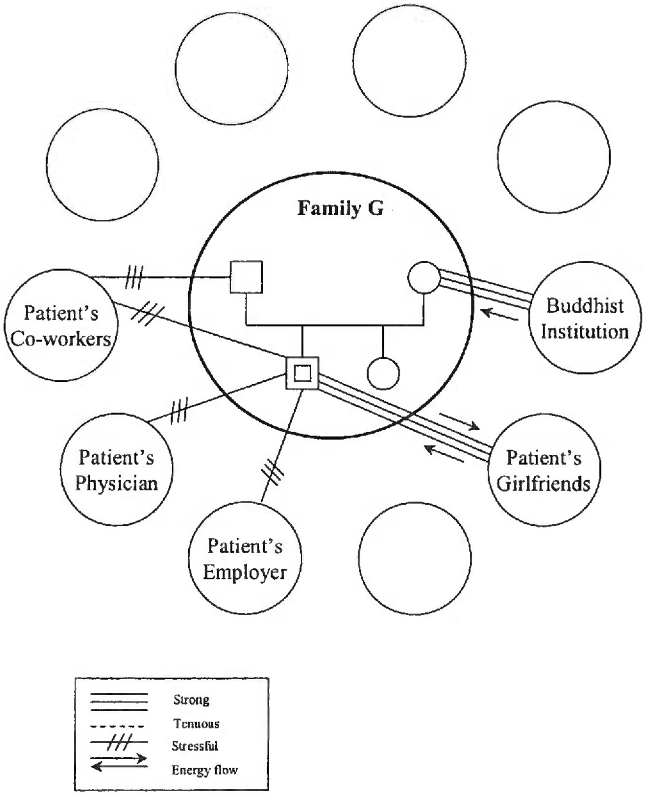

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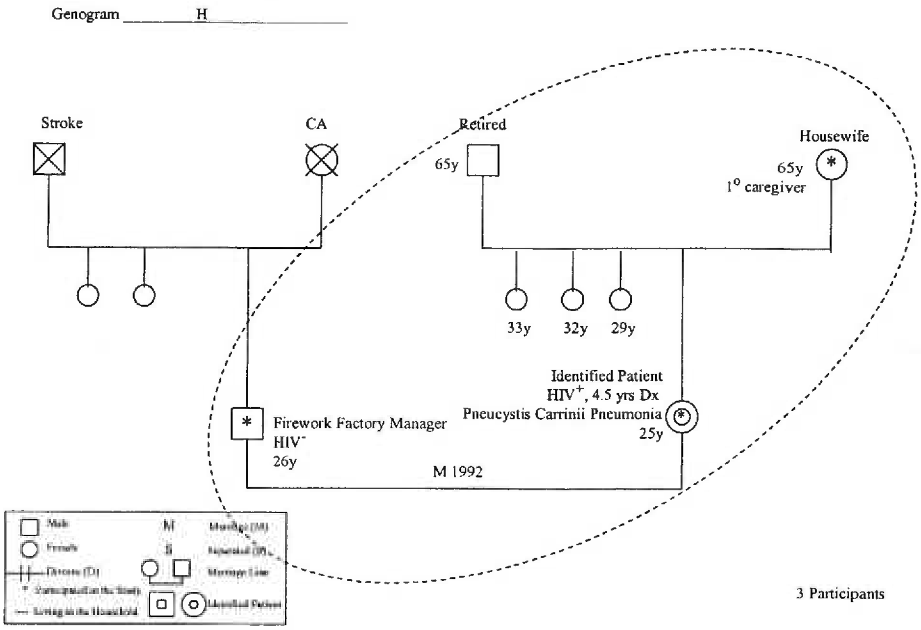

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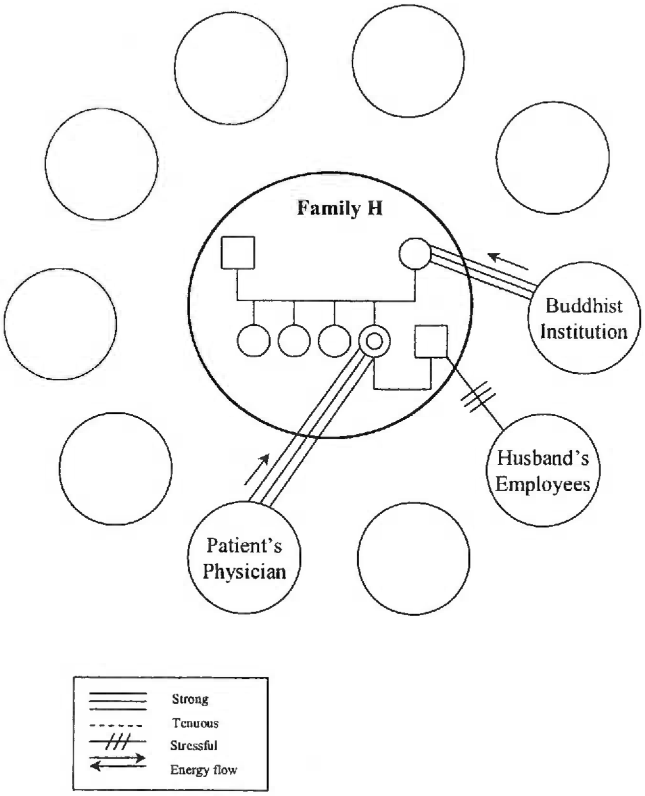
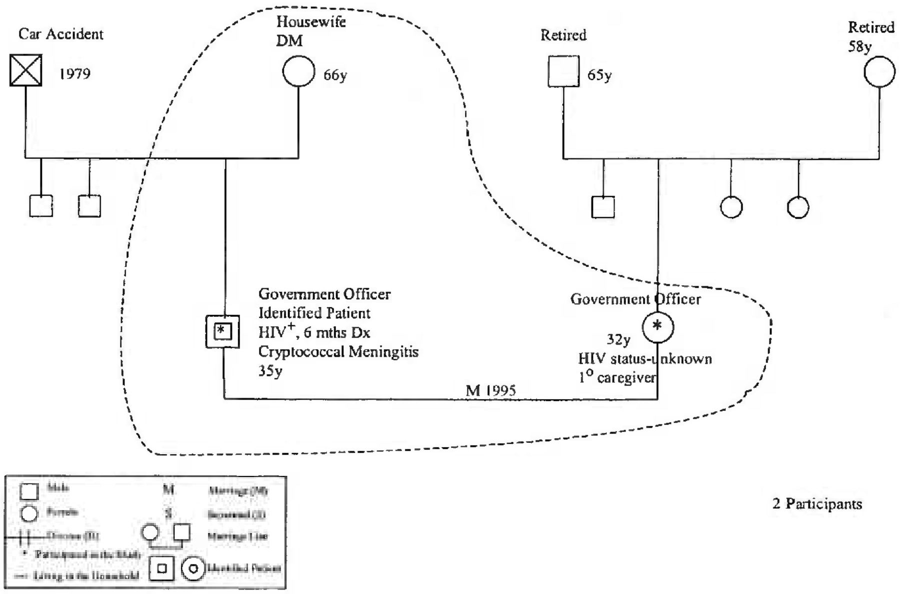
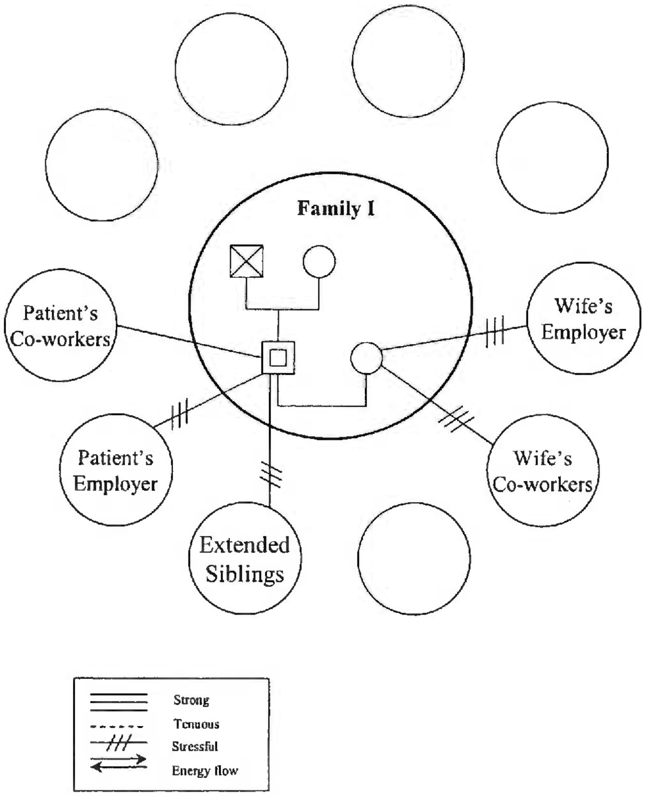


# GENOGRAM

Genogram I

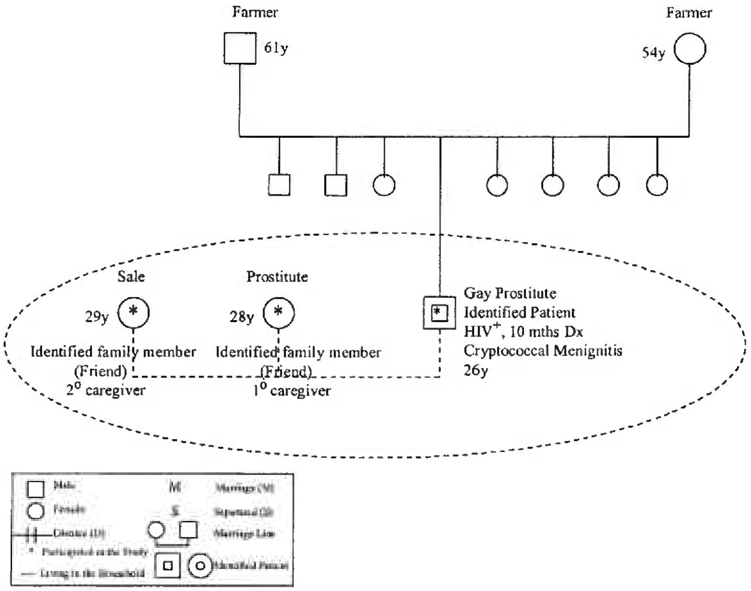


# ECOMAP



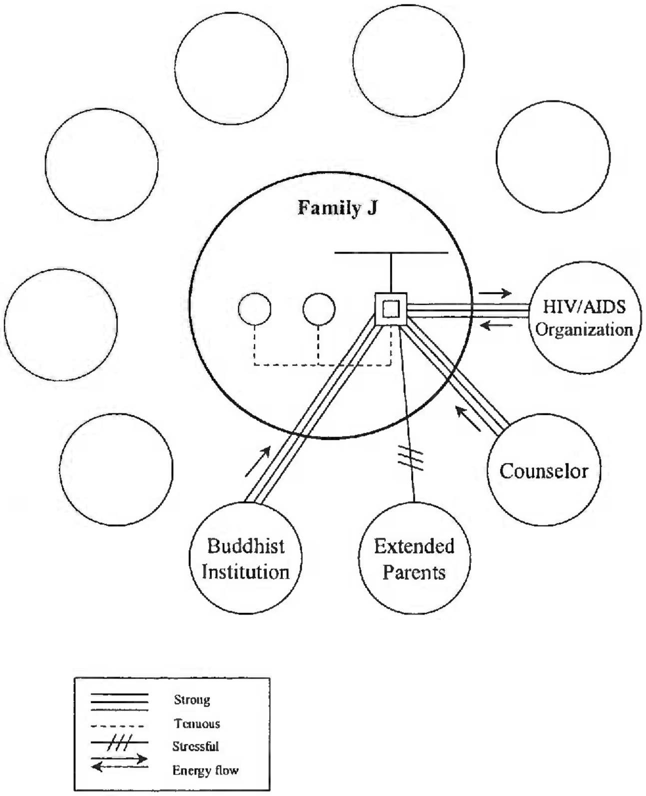
# GENOGRAM

Genogram _______J______________

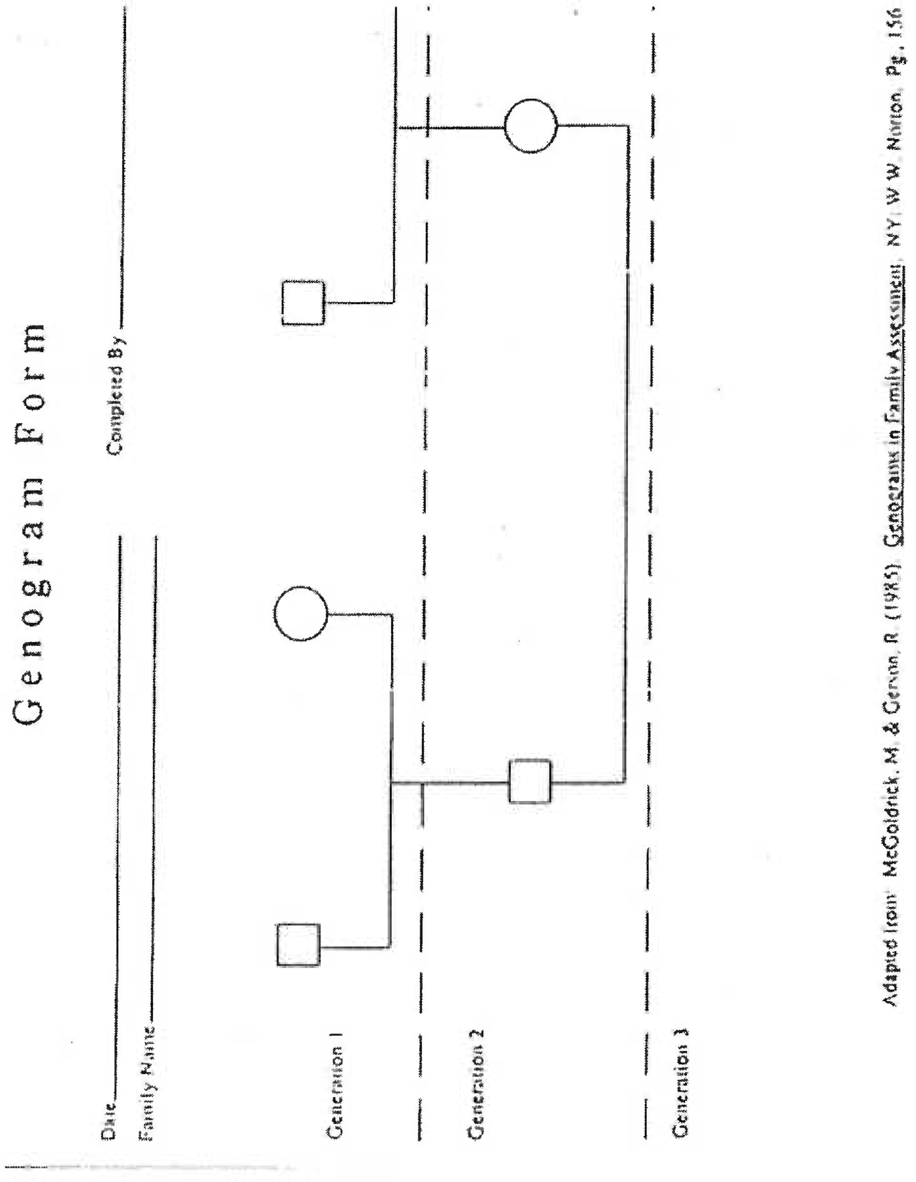


3 Participants

# ECOMAP



# Appendix B

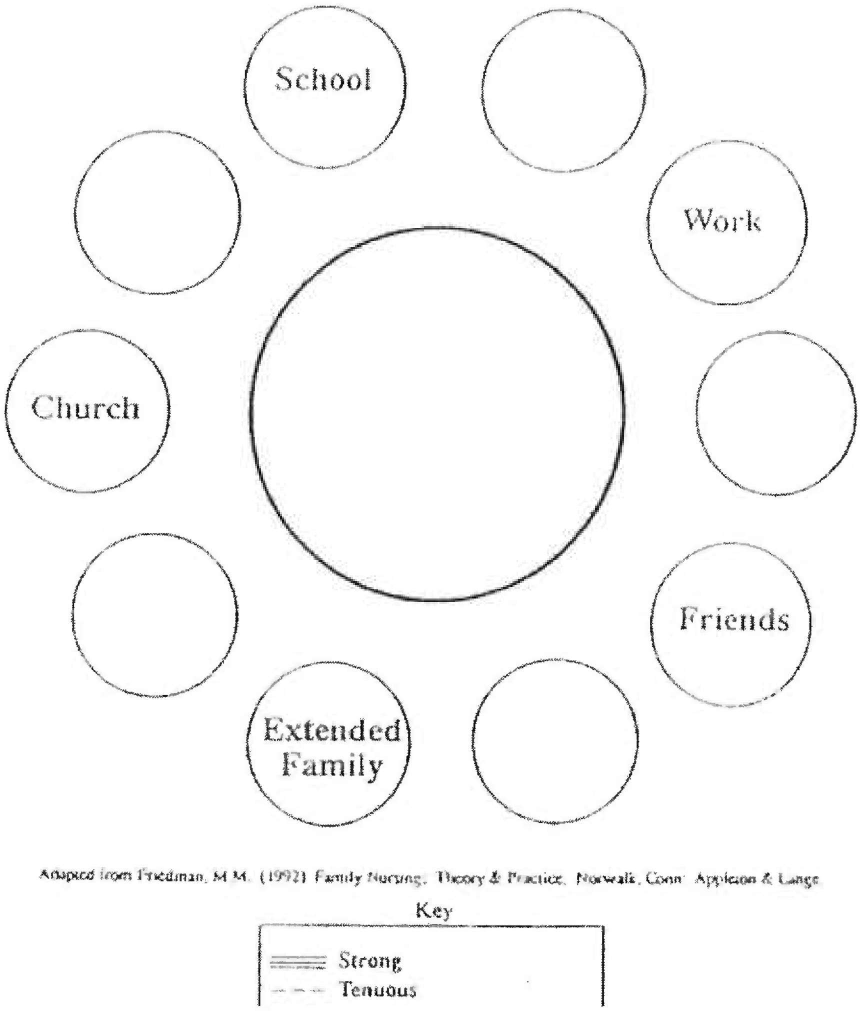


Adapted from: McGoldrick, M. & Gerson, R. (1985). Genograms in Family Assessment. NY: W.W. Norton. Pg. 156

*Note.* From *Family assessment and intervention* (p. 180), by S. M. H. Hanson, 2001. In S. M. H. Hanson (Ed.), *Family health care nursing: Theory, practice, and research.* (2nd ed.), Philadelphia: F.A. Davis. Copyright 2001 by F.A. Davis Company. Reprint with permission of the author.

# Appendix C

ECOMAP FORM



Adapted from Friedman, M.M. (1992) Family Nursing: Theory & Practice. Norwalk, Conn: Appleton & Lange

*Note*. From *Family assessment and intervention* (p. 186), by S. M. H. Hanson, 2001. In S. M. H. Hanson (Ed.), *Family health care nursing: Theory, practice, and research.* ($2^{nd}$ ed.), Philadelphia: F.A. Davis. Copyright 2001 by F.A. Davis Company. Reprint with permission of the author.

## Appendix D

## Family Interview Guide

ID # ____________________

**Section I : Demographic Questions** (ask the patient)

Family total monthly income - current ______________

- prior to illness ______________

Family members' employment status: ________________________________________

________________________________________________________________________

**Section II: HIV/AIDS Information** (Chart Review)

Stage of the disease: ______________________________ CD4 count ___________

Route of disease transmission: ______________________________

Time since diagnosis was established: ________________

Time between diagnosis and disclosure ________________

Opportunistic infections so far? ______________________________

How many times hospitalized? ______________________________

**Section III: HIV/AIDS Questions** (ask the patient)

1. When were the family members told about the HIV/AIDS diagnosis?

2. Who did you tell?

3. How did they respond?

ID # ____________________

4. Has your family had any experience with HIV/AIDS before?

5. Who has experience with HIV/AIDS before?

6. Who is your primary caregiver?

**Section IV: Stressors, Strengths, and Supports Questions** (ask family together)

7. What are the problems and stressful situations in your daily life which are not related to HIV/AIDS?

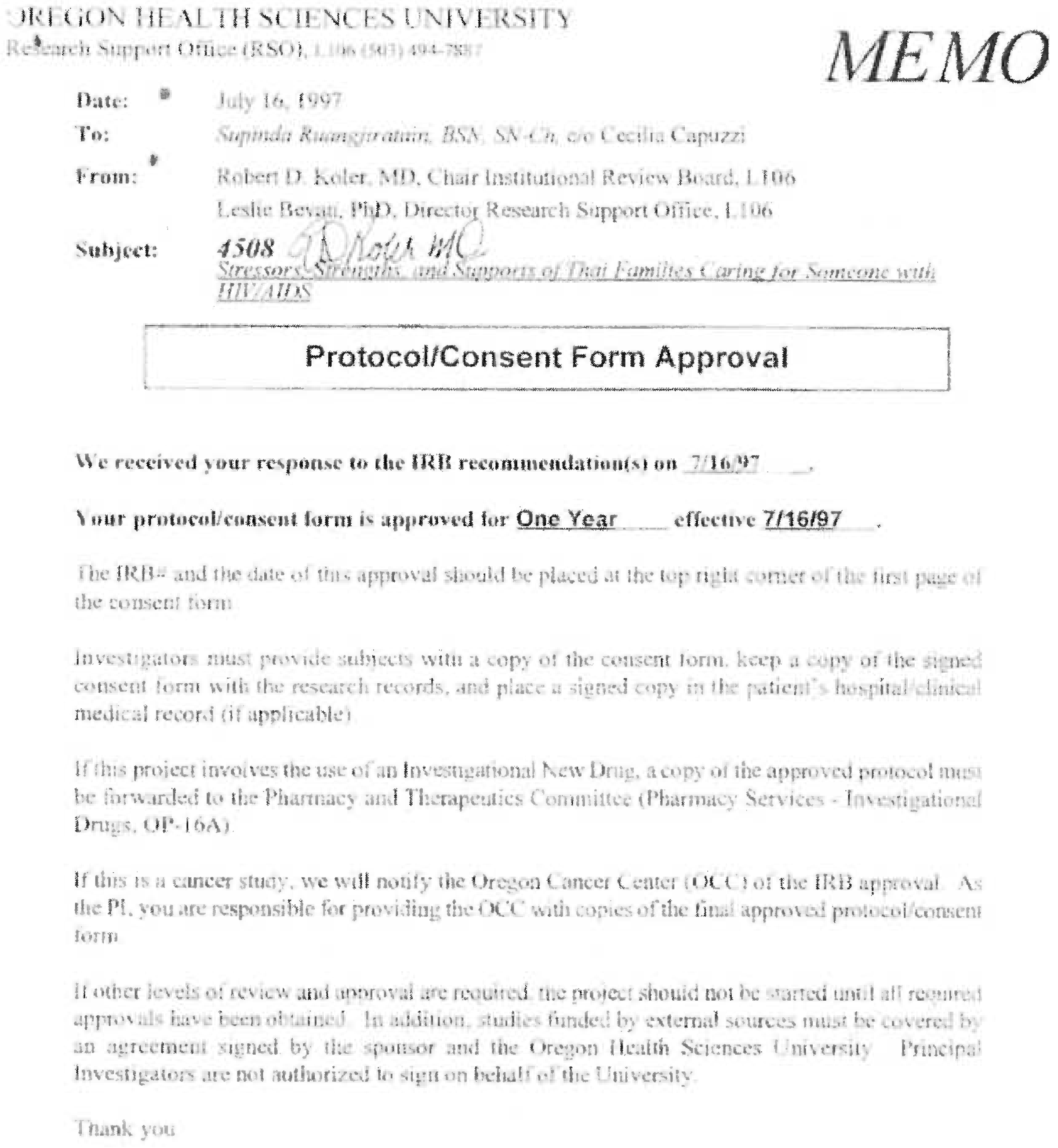
8. What are the problems and stressful situations associated with HIV/AIDS which you have experienced?

9. What are the strengths that have helped you in dealing with those problems and stressful situations identified above?

10. What is your family supports that has not been included in the ecomap?

# Appendix E

## Protocol/Consent Form Approval



OREGON HEALTH SCIENCES UNIVERSITY
Research Support Office (RSO), L106 (503) 494-7887

**MEMO**

**Date:** July 16, 1997

**To:** *Supinda Ruangjiratain, BSN, SN-Ch,* c/o Cecilia Capuzzi

**From:** Robert D. Koler, MD, Chair Institutional Review Board, L106
Leslie Bevan, PhD, Director Research Support Office, L106

**Subject:** ***4508*** RD Koler MD
*Stressors, Strengths, and Supports of Thai Families Caring for Someone with HIV/AIDS*

**Protocol/Consent Form Approval**

**We received your response to the IRB recommendation(s) on** 7/16/97.

**Your protocol/consent form is approved for** One Year **effective** 7/16/97.

The IRB# and the date of this approval should be placed at the top right corner of the first page of the consent form.

Investigators must provide subjects with a copy of the consent form, keep a copy of the signed consent form with the research records, and place a signed copy in the patient's hospital/clinical medical record (if applicable).

If this project involves the use of an Investigational New Drug, a copy of the approved protocol must be forwarded to the Pharmacy and Therapeutics Committee (Pharmacy Services - Investigational Drugs, OP-16A).

If this is a cancer study, we will notify the Oregon Cancer Center (OCC) of the IRB approval. As the PI, you are responsible for providing the OCC with copies of the final approved protocol/consent form.

If other levels of review and approval are required, the project should not be started until all required approvals have been obtained. In addition, studies funded by external sources must be covered by an agreement signed by the sponsor and the Oregon Health Sciences University. Principal Investigators are not authorized to sign on behalf of the University.

Thank you

## Appendix F

IRB# 4508
Approved (06/02/1997)

## OREGON HEALTH & SCIENCE UNIVERSITY
## CONSENT FORM

### TITLE

Stressors, Strengths, and Supports of Thai families Caring for Someone with HIV/AIDS.

### PRINCIPAL INVESTIGATOR

| | |
|---|---|
| Supinda Ruangjiratain, RN. | Telephone: 02- 411-5018 |

### ADVISORS

| | |
|---|---|
| Cecelia Capuzzi, RN, Ph.D., | Telephone: 001-503-494-7817 |
| Shirley Hanson, RN, PMHNP, Ph.D., FAAN. | Telephone: 001-503-494-3869 |
| Catherine Salveson, RN, Ph.D. | Telephone: 001-503-494-3558 |

### PURPOSE

You are being asked to participate in this research study because you are a member of a family of two to five members which is caring for someone diagnosed with HIV/AIDS for a minimum of 6 months. The purpose of this study is to identify the stressors, strengths, and supports that your family has experienced when caring for someone with HIV/AIDS. We believe this study will provide information that will help nurses and other health professionals better understand and care for families who are caring for someone with HIV/AIDS.

### PROCEDURES

After you complete this consent form, the hospital medical chart of the family member with HIV/AIDS will be reviewed by the investigator with the hospital's permission and verbal consent from your physician. The information about HIV infection history and current immune status will be reviewed from the medical chart. Then, you and your family will be asked about your family members and their relationships over three generations. Next, the relationships between your family members and the community around them will be asked. Your family will then be interviewed together to answer 11 questions. An example of a question is: "What are the problems and stressful situations associated with HIV/AIDS which you have experienced?" The interview will take about an hour and a half. In order to avoid misunderstanding and losing important information, the interview will be audio tape recorded. The interview will be done in the hospital counseling room.

## RISK AND DISCOMFORTS

The interview questions may cause you to recall unpleasant past events. Different answers to the questions might cause conflicts in the family. If any one of the family members wants to stop the interview, the investigator will do so. If the family needs assistance during and/or after the interview, a referral to appropriate resources at the hospital will be made.

## BENEFITS

You may or may not personally benefit from participating in this study. However, by participating, you may contribute new information which may benefit families who are caring for someone with HIV/AIDS in the future.

## CONFIDENTIALITY

Information you provide to the investigator will be kept strictly confidential. The recorded audio tapes will be kept in a locked file and will be destroyed once they are transcribed. All personal identifying information will be deleted in the typed record. Your consent forms will be kept separately in a locked file. Only code numbers will be written on the data collection form. The list of participants' names and code numbers will be kept strictly confidential and will be destroyed at the end of the study. Collected data will be kept in a locked file. The transcripts will be kept approximately five years and may be used in future related research. After that time, the transcripts will be destroyed. The findings will be reported in anonymous form. Neither the names nor identities of the participants will be used for publication or publicity purposes.

## COST

There will be no costs to you for participating in this study.

## LIABILITY

The Oregon Health & Science University, as a public institution, is subject to the Oregon Tort Claims Act, and is self-insured for liability claims. If you suffer any injury from this research project, compensation would be available to you only if you establish that the injury occurred through the fault of the University, its officers, or employees. However, you have not waived your legal rights by signing this form. If you have further questions, please call Medical Services Director at 001-503-494-8014.

PARTICIPATION

Supinda Ruangjiratain (phone: 02-411-5018) has offered to answer any questions you may have about this study. If you have any questions regarding your rights as a research subject, you may contact the Oregon Health & Science University Institutional Review Board, USA. at 001-503- 494-7887. Your participation in this research study is voluntary. You or any member of your family may refuse to participate, or may withdraw from this study at any time without affecting your relationship with or treatment at Bamrasnaradura Hospital. You will receive a copy of the consent form. Any family members who are between 15-18 years old will sign another consent form and your signature will be needed as his/her parent/ guardian. Your signature below indicates that you have read the foregoing and agree to participate in this study.

| | |
|---|---|
| Participant | Date |

☐ preferred to give verbal consent

| | |
|---|---|
| Investigator | Date |

# Appendix G

IRB# 4508
Approved (06/02/1997)

## OREGON HEALTH & SCIENCE UNIVERSITY

## CHILD ASSENT FORM

FOR CHILDREN BETWEEN 15-18 YEARS OF AGE:

Nurse Supinda Ruangjiratain has explained this research study. I know how it may or may not help me. I also know that this study will help the nurse know more about my family's problems, resources which my family uses to deal with the problems, and support my family receives when a member of my family has HIV/AIDS.

I have thought about being a part of the study. I have asked and gotten answers to my questions. I agree to be in this study. I know that I don't have to agree to be in it. Even though I agree to be in it now, I know I may not want to later. I know that I may stop being in the study at any time.

Participant ____________________ Date ____________

☐ preferred to give verbal consent

Parent / Guardian ____________________ Date ____________

☐ preferred to give verbal consent

Investigator ____________________ Date ____________

## Appendix H

## Consent Form (Thai Version)

**IRB#** 4508
**อนุมัติ** (06/02/1997)

# OREGON HEALTH & SCIENCE UNIVYERSITY
# ใบยินยอมเข้าร่วมการวิจัย

**ชื่อเรื่องวิจัย** : สิ่งเร้าความเครียด ความเข้มแข็ง และการสนับสนุนช่วยเหลือของครอบครัวไทยที่ดูแลผู้ติดเชื้อเอดส์ / ผู้ป่วยโรคเอดส์
**ชื่อผู้วิจัยหลัก** : สุพินดา เรืองจิรัษเฐียร วทบ.พยาบาล **โทรศัพท์** 02-411-5018
**ที่ปรึกษา** : Cecelia Capuzzi, RN, Ph.D. **โทรศัพท์** 001-503-494-7817
Shirley Hanson, RN, PMHNP, Ph.D.FAAN **โทรศัพท์** 001-503-494-3869
Catherine Salveson, RN, Ph.D. **โทรศัพท์** 001-503-494-3558

**วัตถุประสงค์** :

ท่านถูกเชิญให้เข้าร่วมในการวิจัยนี้ เนื่องจากท่านเป็นผู้ป่วยหรือสมาชิกของครอบครัวขนาด 2-5 คน ที่กำลังดูแลสมาชิกที่ติดเชื้อเอดส์ / ป่วยเป็นโรคเอดส์มาแล้วอย่างน้อย 6 เดือน การศึกษานี้มีวัตถุประสงค์ เพื่อศึกษาถึง สิ่งเร้าความเครียด ความเข้มแข็งของครอบครัวของท่าน เมื่อต้องให้การดูแลผู้ติดเชื้อเอดส์ / ผู้ป่วยโรคเอดส์ และการสนับสนุนช่วยเหลือที่ครอบครัวของท่านได้รับ การศึกษานี้จะให้ข้อมูลซึ่งช่วยให้พยาบาล และเจ้าหน้าที่สาธารณสุขอื่นๆ เข้าใจ และให้การดูแลช่วยเหลือผู้ติดเชื้อเอดส์ / ผู้ป่วยโรคเอดส์ และครอบครัวซึ่งดูแลผู้ติดเชื้อ / ผู้ป่วยได้ดียิ่งขึ้นและ ตรงกับความ ต้องการมากขึ้น

**ขั้นตอนการศึกษา** :

ผู้ป่วยทุกรายที่เข้าร่วมการวิจัยนี้ ได้ผ่านขั้นตอนการให้คำปรึกษาเรียบร้อยแล้วจากเจ้าหน้าที่ของกลุ่มงานแนะแนว โรงพยาบาลบำราศนราดูล หลังจากที่ท่านเซ็นยินยอมเข้าร่วมการวิจัยแล้ว ผู้วิจัยจะศึกษาประวัติการรักษาของท่าน จากทะเบียนประวัติของโรงพยาบาล โดยความยินยอมของโรงพยาบาล และแพทย์เจ้าของไข้ของท่าน ผู้วิจัยจะรวบรวม ข้อมูลเกี่ยวกับประวัติการติดเชื้อ และระดับภูมิคุ้มกันล่าสุดของท่าน หลังจากนั้น ท่านและครอบครัวจะถูกสัมภาษณ์ เกี่ยวกับสมาชิกในครอบครัวสามรุ่น และความสัมพันธ์ระหว่างสมาชิกในครอบครัว รวมทั้งความสัมพันธ์ของครอบครัวท่านกับเพื่อนบ้านและชุมชน ต่อจากนั้น ครอบครัวของท่านจะตอบคำถามที่ผู้วิจัยถามร่วมกัน 11 คำถาม ตัวอย่างคำถาม ได้แก่ “ท่านมีปัญหาหรือความเครียดใดบ้างที่เกิดขึ้นจากการที่สมาชิกในครอบครัวติดเชื้อ / ป่วยเป็นโรคเอดส์” การสัมภาษณ์ทั้งหมดจะใช้เวลาประมาณ หนึ่งชั่วโมงครึ่ง การสัมภาษณ์จะถูกบันทึกเทป เพื่อให้ผู้วิจัยเก็บรวบรวมคำตอบ ของท่านได้ถูกต้องและครบถ้วน การสัมภาษณ์จะกระทำในห้องให้คำปรึกษาภายในหอผู้ป่วย

**ความเสี่ยงและสิ่งไม่พึงประสงค์** :

คำถามบางคำถามอาจทำให้ท่านนึกถึงเหตุการณ์ไม่สบายใจในอดีต คำตอบที่แตกต่างกันของสมาชิกแต่ละคนอาจทำให้เกิดความขัดแย้งภายในครอบครัว หากท่านใดต้องการหยุดให้สัมภาษณ์ ผู้วิจัยจะกระทำตามความต้องการนั้น หากท่านและครอบครัวต้องการความช่วยเหลือใด ๆ ในระหว่างหรือหลังการให้สัมภาษณ์ ผู้วิจัยจะประสานงานกับผู้ให้การช่วยเหลือในโรงพยาบาลที่เหมาะสม และส่งท่านไปรับความช่วยเหลือต่อไป

**ประโยชน์ที่จะได้รับ** :

ท่านอาจจะได้รับหรือไม่ได้รับประโยชน์โดยส่วนตัวจากการเข้าร่วมการวิจัยนี้ อย่างไรก็ตามการเข้าร่วมการวิจัยนี้ ท่านอาจจะมีส่วนช่วยในการให้ข้อมูลใหม่ ๆ ซึ่งอาจจะเป็นประโยชน์กับครอบครัวอื่น ๆ ที่กำลังดูแลผู้ติดเชื้อเอดส์ / ผู้ป่วย โรคเอดส์ในอนาคต

**การเก็บรักษาความลับ** :

ผู้วิจัยจะเก็บข้อมูลทั้งหมด ที่ท่านให้สัมภาษณ์ไว้เป็นความลับสุดยอด เทปบันทึกเสียงจะถูกเก็บไว้ในตู้ล็อคกุญแจ และจะถูกทำลายเมื่อคำตอบของท่านถูกถอดและบันทึกลงในกระดาษโดยตัดข้อมูลส่วนบุคคลเกี่ยวกับตัวท่านออก ใบยินยอมเข้าร่วมการวิจัย จะถูกเก็บในตู้ล็อคกุญแจ ตัวเลขและตัวอักษรจะถูกใช้เป็นรหัสแทนตัวของท่าน ในการบันทึก ข้อมูล รายชื่อของ ผู้เข้าร่วมวิจัยและรหัสประจำตัวจะถูกเก็บเป็นความลับและถูกทำลายเมื่อสิ้นสุดการศึกษา ข้อมูลที่ได้มาทั้งหมดจะถูกเก็บไว้ในตู้ล็อคกุญแจ ข้อมูลที่บันทึกไว้จะถูกเก็บไว้ประมาณห้าปี และอาจถูกนำไปใช้ในการศึกษาอื่นที่เกี่ยวข้องในอนาคต ข้อมูลเหล่านี้จะถูกทำลายหลังจากห้าปี การรายงานผลการวิจัยจะนำเสนอข้อมูลโดยรวมแทนรายบุคคล หรือครอบครัว ชื่อ-สกุล และข้อมูล ใด ๆ ที่จะพาดพิงถึงตัวท่านจะไม่ถูกเผยแพร่ต่อสาธารณชนโดยเด็ดขาด

**ค่าใช้จ่าย** :

ท่านไม่ต้องเสียค่าใช้จ่ายใด ๆ ในการเข้าร่วมการวิจัยนี้

**ผู้รับผิดชอบการวิจัย** :

Oregon Health & Science University ซึ่งเป็นสถาบันของรัฐบาลซึ่งอยู่ภายใต้พระราชบัญญัติ Oregon Tort Claims Act มีประกันเพื่อรับผิดชอบต่อการร้องเรียน หากท่านได้รับผลกระทบทางร่างกาย และ/หรือ จิตใจ จากการเข้าร่วมวิจัย ทางมหาวิทยาลัยจะจ่ายค่าทดแทนให้ท่านในกรณีที่ผลกระทบนั้นเกิดจากความผิดของมหาวิทยาลัย เจ้าหน้าที่ หรือ ลูกจ้างของมหาวิทยาลัย อย่างไรก็ตาม ท่านไม่ได้สละสิทธิทางกฎหมายหากเซ็นในยินยอมเข้าร่วมวิจัยนี้ หากมีข้อสงสัยเพิ่มเติม กรุณาโทรไปที่ Medical Services Director โทรศัพท์ 001-503-494-8014

**การเข้าร่วมการวิจัย** :

การเข้าร่วมในการวิจัยนี้ คุณ สุพินดา เรืองจิรัษเฐียร โทร 02-411-5018 ยินดีที่จะตอบคำถามของท่านทุกข้อ ที่เกี่ยวกับการวิจัยนี้ หากท่านมีข้อสงสัยเกี่ยวกับสิทธิของท่าน ในฐานะ ผู้เข้าร่วมการวิจัย ท่านสามารถติดต่อได้ที่ Oregon

Health & Science University Institutional Review Board, USA โทรศัพท์ 001-503-494-7887 การเข้าร่วมการวิจัยนี้เป็นความสมัครใจของท่านและครอบครัว โดยท่านและครอบครัวมีสิทธิปฏิเสธการเข้าร่วมการวิจัย หรือ ถอนตัวจากการวิจัยนี้ เมื่อใดก็ได้ โดยไม่มีผลกระทบต่อความสัมพันธ์กับโรงพยาบาลบำราศนราดูร หรือการรักษาที่โรงพยาบาลนี้แต่อย่างใด ท่านจะได้รับสำเนาเอกสารนี้ 1 ชุด ลายเซ็นต์ของท่านข้างล่างนี้ แสดงว่า ท่านได้อ่าน ข้อความข้างต้น และยินยอมเข้าร่วมการวิจัยนี้ ผู้เข้าร่วมการวิจัยที่มีอายุ ระหว่าง 15-18 ปี จะเซ็นต์ให้ความยินยอม เข้าร่วมวิจัยตามเอกสารสำหรับผู้เยาว์ โดยบิดามารดาหรือผู้ปกครองเซ็นต์ให้ความยินยอมให้ผู้นั้นเข้าร่วมการวิจัย

| | |
|---|---|
| ______________________________ | __________________ |
| ผู้เข้าร่วมวิจัย | วันที่ |

☐ ต้องการให้คำยินยอมด้วยวาจา

| | |
|---|---|
| ______________________________ | __________________ |
| ผู้วิจัย | วันที่ |

## Appendix I

## Child Assent Form (Thai Version)

**IRB#** 4508
**อนุมัติ** (06/02/1997)

# OREGON HEALTH & SCIENCE UNIVERSITY
# ใบยินยอมเข้าร่วมการวิจัย

**สำหรับผู้เยาว์อายุ 15-18 ปี:**

คุณพยาบาล สุพินดา เรืองจิรัษเฐียร ได้แนะนำและ อธิบายการวิจัยนี้ให้ข้าพเจ้าฟัง ข้าพเจ้าทราบว่าการวิจัยนี้ อาจช่วยหรือไม่ช่วยข้าพเจ้า แต่จะช่วยให้พยาบาลทราบปัญหา และความเข้มแข็งของครอบครัวข้าพเจ้า รวมทั้งความช่วยเหลือสนับสนุนที่ครอบครัวข้าพเจ้าได้รับเพื่อใช้ในการเผชิญปัญหา เมื่อสมาชิกในครอบครัวป่วยเป็นโรคเอดส์

ข้าพเจ้าได้ไตร่ตรอง ซักถามและได้รับคำตอบเกี่ยวกับการเข้าร่วมการวิจัย ข้าพเจ้าสมัครใจที่จะเข้าร่วมการวิจัยนี้ โดยข้าพเจ้าทราบว่า ข้าพเจ้าไม่จำเป็นต้องเข้าร่วมการวิจัยนี้ก็ได้ และถึงแม้ข้าพเจ้าเข้าร่วมการวิจัยนี้แล้ว ข้าพเจ้าทราบว่าข้าพเจ้าสามารถถอนตัวได้ทุกเวลาหากข้าพเจ้าไม่ต้องการร่วมการวิจัยในภายหลัง

____________________________ ________________
ผู้เข้าร่วมวิจัย วันที่

☐ ต้องการให้คำยินยอมด้วยวาจา

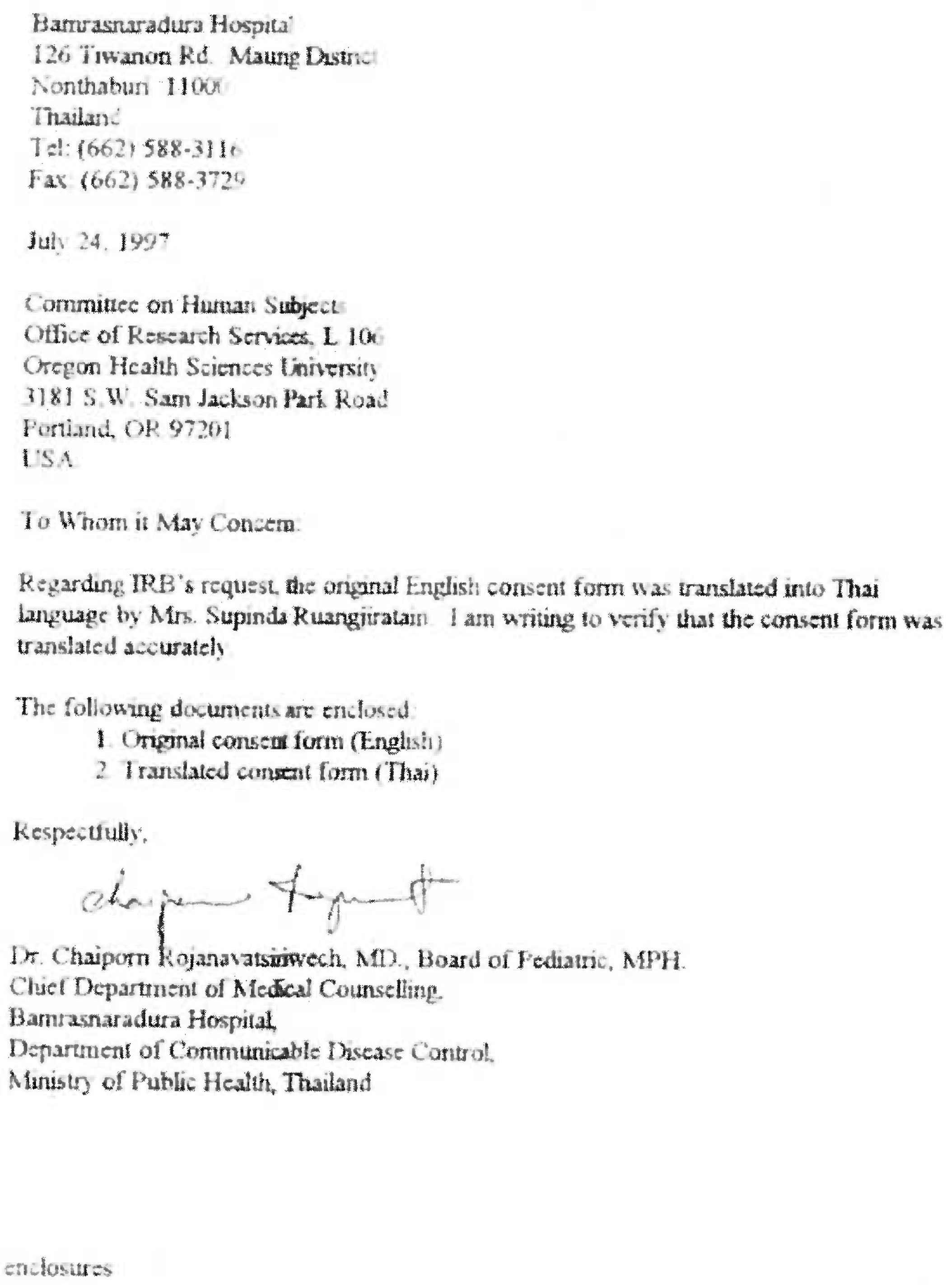
____________________________ ________________
บิดา/มารดา/ผู้ปกครอง วันที่

☐ ต้องการให้คำยินยอมด้วยวาจา

____________________________ ________________
ผู้วิจัย วันที่

# Appendix J

## Letter of Certified Corrected Translation of Consent Form



Bamrasnaradura Hospital
126 Tiwanon Rd. Maung District
Nonthaburi 11000
Thailand
Tel: (662) 588-3116
Fax: (662) 588-3729

July 24, 1997

Committee on Human Subjects
Office of Research Services, L 106
Oregon Health Sciences University
3181 S.W. Sam Jackson Park Road
Portland, OR 97201
USA

To Whom it May Concern:

Regarding IRB's request, the original English consent form was translated into Thai language by Mrs. Supinda Ruangjiratain. I am writing to verify that the consent form was translated accurately.

The following documents are enclosed:

1. Original consent form (English)
2. Translated consent form (Thai)

Respectfully,

Dr. Chaiporn Rojanavatsiriwech, MD., Board of Pediatric, MPH.
Chief Department of Medical Counselling,
Bamrasnaradura Hospital,
Department of Communicable Disease Control,
Ministry of Public Health, Thailand

enclosures

# Appendix K

# Letters of Agreement

ที่ ทม 0804/๕๙๒

คณะพยาบาลศาสตร์ มหาวิทยาลัยมหิดล
บางกอกน้อย กรุงเทพฯ 10700

๖ กุมภาพันธ์ 2540

เรื่อง ขอความร่วมมือในการวิจัย

เรียน ผู้อำนวยการโรงพยาบาล[illegible]

สิ่งที่ส่งมาด้วย โครงร่างวิทยานิพนธ์ จำนวน 1 ฉบับ

เนื่องด้วย นางสาวสุพินดา ไรติกีรติเวช อาจารย์ประจำภาควิชาการพยาบาล[illegible]สูติศาสตร์ คณะพยาบาลศาสตร์ มหาวิทยาลัยมหิดล กำลังศึกษาในระดับปริญญาเอก สาขาพยาบาลศาสตร์ ณ Oregon Health Science University ประเทศสหรัฐอเมริกา ได้ดำเนินการศึกษาวิจัยเพื่อเป็นวิทยานิพนธ์ เรื่อง " สิ่งเร้าความเครียดและความต้องการของครอบครัวผู้ป่วยโรค[illegible] " ในการศึกษาวิจัยครั้งนี้ผู้วิจัยใคร่ขอความร่วมมือในการเก็บข้อมูลผู้ป่วยโรค[illegible]ที่มารับการรักษา ณ โรงพยาบาล[illegible] ในระหว่างเดือนกุมภาพันธ์ ถึงเดือนมีนาคม 2540 ดังรายละเอียดในโครงร่างวิทยานิพนธ์ที่แนบมาด้วย

จึงเรียนมาเพื่อขอความอนุเคราะห์ให้ นางสาวสุพินดา ไรติกีรติเวช ได้ทำการเก็บข้อมูลดังกล่าว คณะฯ หวังเป็นอย่างยิ่งในความอนุเคราะห์ และขอขอบคุณเป็นอย่างสูงมา ณ โอกาสนี้ด้วย

ขอแสดงความนับถือ

รองศาสตราจารย์ ดร.ทัศนา บุญทอง
คณบดีคณะพยาบาลศาสตร์

ศูนย์การแปลนานาชาติ
**INTERLANGUAGE TRANSLATION CENTER**

- 501 [illegible] กทม. 10300 โทร 243-2018, 243-2109, 241-4109 FAX [illegible]
- 552-554 [illegible] กทม 10500 โทร 252-4307, 252-9177 FAX [illegible]
- เลขที่ 1 สุขุมวิทซอย 1 ถ.สุขุมวิท โทร 254-1677, 252-3677 FAX: 255-1998
- เลขที่ 57/3 ถ.ใหญ่ ปทุมวัน โทร 252-7450 FAX: 252-7450

(Translation)

No. Thor.Mor. 0804/892

Faculty of Nursing,
Mahidol University,
Bangkok Noi, Bangkok 10700

February 5, 1997

Subject: Request for Cooperation in Research

To: The Director, Bamrasnaradura Hospital

Enclosure: Outline of Thesis - 1 copy

Mrs. Supinda Ruangjiratain instructor of the Department of Public Health Nursing, Faculty of Nursing of Manidol University, who is studying at a master's degree level in the Nursing branch at Oregon Health Science University, the United States, has conducted a research for the preparation of a thesis under the title: "Stressors and Strengths of Thai Families with HIV/AIDS." In this research, the researcher would like to request for cooperation in collecting data on HIV/AIDS patients who receive treatment at Bamrasnaradura Hospital between July and August 1997 as indicated in detail in the outline of thesis enclosed herewith.

We therefore request for your assistance is allowing Mrs. Supinda Ruangjiratain to collect the said data. The faculty fully hopes to receive your kind assistance and takes this opportunity to thank you.

รับรองการแปลถูกต้อง
Certified Correct Translation
อรี สุพันธ์นันท์
Aree Suphanthanant

Yours respectfully,

- signed -

Association Professor. Dr. Thatsana Bunthong
Dean of Faculty of Nursing

Department of Public Health Nursing

เลขรับ 170
วันที่ 20 ก.พ. 2540
เวลา 11.55

# บันทึกข้อความ

**ส่วนราชการ** โรงพยาบาลบำราศนราดูร ฝ่ายธุรการ โทร.5883116 โทรสาร 5883729
**ที่** สธ 0410.1/ 301 **วันที่** 20 กุมภาพันธ์ 2540
**เรื่อง** ขออนุญาตเก็บข้อมูล

เรียน อธิบดีกรมควบคุมโรคติดต่อ

ด้วยคณะพยาบาลศาสตร์ มหาวิทยาลัยมหิดล ได้แจ้งความประสงค์ขออนุญาตให้ นางสาวสุพินดา โชติกีรติเวช อาจารย์ประจำภาควิชาการพยาบาลสาธารณสุขศาสตร์ คณะพยาบาลศาสตร์ มหาวิทยาลัยมหิดล เก็บข้อมูลผู้ป่วยโรคเอดส์ที่มารับบริการรักษา ณ โรงพยาบาลบำราศนราดูร ระหว่างเดือนกุมภาพันธ์-มีนาคม 2540 เพื่อประกอบในการศึกษา วิจัย เพื่อเป็นวิทยานิพนธ์ ตามรายละเอียดในหนังสือคณะพยาบาลศาสตร์ มหาวิทยาลัยมหิดล ที่นำเสนอมาพร้อมนี้

โรงพยาบาลได้เสนอคณะกรรมการวิจัยของโรงพยาบาลพิจารณาแล้ว ซึ่งมีมติเห็นควรอนุมัติให้นักศึกษารายดังกล่าวข้างต้น เก็บข้อมูลในครั้งนี้จากโรงพยาบาลได้

จึงเรียนมาเพื่อโปรดพิจารณา จะเป็นพระคุณ

(นางอังคณา เชาวะวณิช)
นายแพทย์ 8 วช. ด้านเวชกรรม สาขาสูติ-นรีเวชกรรม
รักษาราชการแทนผู้อำนวยการโรงพยาบาลบำราศนราดูร

โรงพยาบาลบำราศนราดูร นนท.
เลขรับ 1185
วันที่ 3 มี.ค. 40
เวลา 8.30

25 ก.พ. 40

**(นายชนะ ตันจันทร์พงศ์)**
**รองอธิบดี ปฏิบัติราชการแทน**
**อธิบดีกรมควบคุมโรคติดต่อ**

ศูนย์การแปลนานาชาติ
INTERLANGUAGE TRANSLATION CENTER
- 501 ถ.สามเสน ข้างหอสมุดแห่งชาติ ท่าวาสุกรี เขตดุสิต กทม. 10300 โทร. 243-2018, 243-2109, 241-4309 FAX 241-5686
- 552-554 อาคารสมาคมภาษาอังกฤษแห่งประเทศไทย สี่แยกเพลินจิต ถ.เพลินจิต กทม. 10500 โทร. 252-4307 252-9171 FAX 252-917
- เลขที่ 1 สุขุมวิทซอย 1 ถ.สุขุมวิท โทร. 254-1677, 252-3877 FAX. 255-1998
- เลขที่ 57/3 ถ.วิทยุ ปทุมวัน โทร. 252-7450 FAX 252-7450

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(Translation)

MEMORANDUM

Government Agency: Bamrasnaradura Hospital, Administrative Section,
Tel: 5883116 Fax: 5883729

No. Sor.Thor. 0410.1/801 Date: February 20, 1997

Subject: Request for Permission to Collect Data

To: The Director-General of Communicable Disease Control Department

The Faculty of Nursing, Mahidol University, and requested for permission for Mrs. Supinda Ruangjiratain, instructor of the Department of Public Health Nursing, Faculty of Nursing, Mahidol University, to collect data on HIV/AIDS Patients who receive treatment at Bamrasnaradura Hospital between July and August 1997 in order to use data for study and research in the preparation of a thesis. Details are in the letter of the Faculty of Nursing, Mahidol University, enclosed herewith.

We submitted the request to the Research Committee of the hospital for consideration and the Committee has resolved that permission should be granted to the above student to collect data at the hospital.

The above is presented for your kind consideration, for which we will be grateful.

- signed -
(Mrs. Atchara Chaowawanit)
Physician, P.C.8., Medicine in Obsteltrics and Gynaecology
Acting Director of Bamrasnaradura Hospital

Approved
- signed -
(Mr. Chana Tanchanphong)
Deputy Director-General
for Director-General of
Communicable Disease Control Department

รับรองการแปลถูกต้อง
Certified Correct Translation

# Appendix L

## Research Description

This research description will be read to the patient by an on-site staff nurse to introduce the research of "Stressors, Strengths, and Social Supports of Thai families caring for persons living with HIV/AIDS" conducted by Mrs. Supinda Ruangjiratain, RN. If the patient is interested in the research, he/she will be asked for permission to be contacted by the researcher.

> "The research of "Stressors, Strengths, and Social Supports of Thai families caring for persons living with HIV/AIDS" will study the patients receiving care at Bamrasnaradura Hospital and their families. The purpose of this study is to identify the stressors, strengths, and social supports of Thai families who are caring for someone with HIV/AIDS to understand the families' experiences. This study does not involve an experimental treatment or intervention given to patients, but rather is solely the interview. An example of the questions is: "What are the problems and stressful situations associated with HIV/AIDS which you have experienced?" The participants in each family will be interviewed together in the hospital counseling room. The interview will take about an hour and a half. Confidentiality will be assured through the use of code numbers. Collected data will be kept in a locked file. Neither the name nor identity of the participants will be used for publication or publicity purposes."
>
> "The research results will assist nurses in providing care to the HIV/AIDS patients and their families and will be used to develop educational and home care programs to assist them in the future. This research has been approved, and permission of the hospital research committee has been obtained."