#### **CHAPTER 4**

#### FINDINGS AND DISCUSSION

This chapter is organized into two sections: findings and discussion. The findings generated from Colaizzi's method of data analysis and discussion about the findings are presented as follows

### **Findings**

This section presents the results to answer the research questions of the study that is "what is it like to receive family caregiving for people living with HIV/AIDS (PLWAs)?" The fourteen informants of the study were PLWAs who lived with their families in Chiang Mai province, Thailand. The data were collected through the indepth interviews. The results were divided into 2 parts as follows:

Part 1: Characteristics of the informants

Part 2: Experiencess of receiving family caregiving among people living with AIDS (PLWAs). This part is presented into two levels: themes and categories as follows:

The themes can be divided into three main themes: caring, roles of family members and lengthening life. The first theme 'caring' can be subdivided into two categories which are the will power from family members and the need of

psychological support. The second theme 'care received from family members' can be subdivided into two categories which are the self-devotion of family members and the caregiving due to duty. The last theme is 'lengthening life' which can be subdivided into two categories which are the essentials for long life and supporting for survival.

### Characteristics of the Informants

The informants in this study were fourteen PLWAs consisting of nine female (64.29%) and five male (35.71%). The age ranged between 25-38 years old and the average age was 31.43 years (SD=4.07). Of the fourteen respondents, ten informants had the extended families and the other four informants had the nuclear families. Seven informants had mothers as their major family caregivers whereas five informants had the spouses as major family caregivers. One informant has her father as her major family caregiver and the other one informant has her younger brother as her family caregiver. The time period during which the informants knew they were HIV or AIDS infected ranged between 1-8 years as shown in table 1.

Table 1: Characteristics of the Informants

Characteristics	Number
Gender	0
Male ©	5
Female	9
Age	
25-30	6
31-35	5
36-40	3
Religion	
Buddhism	14
Marital Status	
Single	2
Married	5
Widowed	7
Number of Children	
None	6
One	6
Two	2
Type of Family	
Nuclear	4
Extened	10
Major Caregiver	
Mother	7
Father	1
Husband/Wife	5
Younger brother	1

# Experiences of Receiving Family Caregiving among People Living with HIV/AIDS

The researcher analyzed the collected data according to the method of Colaizzi (1978 cited in Burns & Grove, 2001; Beck, 1994) by selecting the significant statements from the data which were transcribed word by word from the tape recorded. The significant statements from the interviews, then, were arranged into categories, which were recategorized and grouped into the three themes. These themes would indicate the meanings of experiences from receiving family caregiving as to the perception of PLWAs. The data analysis results in 3 themes and 6 categories. The first theme is caring, which falls into 2 categories such as will power (kumlungjai) and psychological support. The second theme is care received from family members, which consists of self-devotion of family members and the cargiving due to duty. The last theme is lengthening life, which consists of the essentials for long life and supporting for survival.

## Theme 1: Caring

From the experiences of receiving family care, the informants described their receiving of family caregiving as Caring. The meaning of caring was explained as receiving will power (Kumlungjai) and the needs of family caregiving was psychological support. Regarding the will power, the informants indicated that they were encouraged by love, concern, sympathy and showing no disgust from the family members. Meanwhile, the informants also indicated they need caring from their

family members including psychological support from family members based on their understanding. They need to be treated as normal people and wanted close care and touch from their family members.

Table 2: Categories and Subcategories for the Theme: Caring

CATEGORIES AND SUBCATEGORIES	THEME
	(7) <sup>7</sup>
Will Power	
Love	
Concern	
Sympathy	
Consoling	
Forgiving and Not Aggravating	
Consultation	CARING
Relieving Stress	
Showing No Disgust	
Psychological Support	
Understanding	
Treating as Normal People	
Maintaining Close Care and Touch	

# Will power

The word "will power (kumlungjai)" means the encouragement to create confidence and strength mentally and sentimentally. The informants described will

power as their feeling of proud and warmth received from family members which stemmed from receiving love between family members, concern, sympathy and showing no disgust from their family members.

#### Love

The seven informants from this study perceived that the will power stemmed from receiving the love between family members. The bond was tied between parents and children in the same family that resulted in the love, making the family members be kind to each other. They did not leave the informants but gave such warmth and close attention to the informants that made them feel proud as shown by the following statements:

- "...We're in the same family. Other people are outsiders. Brothers and sisters love each other so the will power can be received. We're from the same blood and when I'm in trouble they have to help me whatever the trouble is." (Lar)
- "...Because I'm sister in law, It makes me feel that they love me and must take care of me. Others who are not in our family might not treat me like them. They love me because I'm a part of the family. They love me." (Pin)
- "... My mom loves me so much. Nobody loves me as much as my mom and dad. They love me... and love everything in me." (Bua)
- "... It's because of love. Without love, they won't take care of me. They love me, love me." (Rut)
- "... I can't work and don't have any earnings. Why do they still live with me? They still live with me because they have tender loving care for me as I am a child. They can't leave me because they take pity on me. The care I've received from my family and wife is caused by love and pity rather than other things. (Dui)

- "... He loves me and doesn't want me to die. I think he takes care of me because of love." (Noy)
- "... I love my mom and so does she. That makes me proud. I feel glad that she hasn't left.me.... The meaning of care given to me is the will power. If she doesn't love me anymore, she might have driven me away." (Ek)

#### Concern

The concern refers to worry, carefulness and watchfulness. The eight informants described that their family members showed their concern. The family members observed the informants' behaviors and emotions. Also, the informants were asked about their symptoms, provided with supplementary drugs and reminded of taking food and medicines by their family members. In addition, the family members showed their perception of the informants' tiredness. When falling sick, the informants were given close attention by their family members who took care of and reminded them to get the treatment or took them to see the doctor in order to prevent them from more serious illnesses. The informants were never deserted or allowed to go out alone as showed by the following remarks:

- "...If I'm ill, they will come to see me, ask about my symptoms, talk with me. I can feel that they still think of me and are concerned about me. That makes me feel encouraged that they didn't desert me." (Kam)
- "... There're some kinds of food that are harmful to me and they warn me not to take those foods... How nice! They're concerned about me and don't want me to fall sick." (Bua)
- "... I feel I get their concern. When I take some food that is bad for me as prohibited by the elders, my younger brother always warns me to be careful of the food that might make me ill... When I get sick at night, my dad hurriedly gets out of his bed to look after me and ask whether I take pills. He often takes care of me when I still have a fever." (Karn)
- "... I feel that my father is worried about me. He always asks my conditions when I fall sick. That means a concern. My mom is also

concerned about me. When I'm ill and have a stomachache and a fever, she always asks me if I'm all right... I feel my mother is worried about me and thinks of me all the time. She wants to share everything with me and tries to seek for me what she thinks I'll like it." (Rut)

- "... They always take care of my health. When they notice me that I'm depressed or a bit strange, they ask about my conditions. What's more, when I have a headache or have some symptoms of illness, they'll quickly come to ask me... Mostly, if I am sick for a few days, I would take paracaetamol and not let anyone know my sickness. I think my mother hides her feelings. She pretends that she doesn't think about me but I observe that when she's alone, she looks worried about me and depressed. If I have a headache or fever, she would take care of me and tell me to see the doctor. I think she's concerned about me but doesn't want to let me know as she's afraid I might think too much.... My mom won't cook food that contains some vegetables like bamboo shoots that might be harmful to me." (Tim)
- "... When I'm extremely stressed and have a severe headache, my husband will take care of me and give me medication, but if I still don't recover, he will suddenly take me to see a doctor. If I tell him that I'm o.k. and don't have to see the doctor, he won't listen to me but insist on taking me to see the doctor as he's afraid that I'll be seriously ill... Concern, my father-in-law concern me, try to take some medicine for me and when I am ill, he will ask me whether I come to see the doctor." (Noy)
- "... Both my mom and dad don't allow me to go out alone. On that sunny day, I had to go out to buy medicines, my dad asked if I was able to go alone. If not, he would take me and he did take me to buy the medicines." (Ked)
- "... My mother doesn't allow me to go out or work. She's concerned and afraid that my health will get worse. She told me not to work because she will take care of me by herself." (Roen)

#### Sympathy

Sympathy refers to a feeling of pity or sorrow; and the expression of sharing in the emotions, opinion, feelings of others. The informants indicated that they got sympathy from their family members who consoled them after knowing that the informants were HIV-positive, depressed and afraid of death. They were forgiven and not aggravated for being HIV positive. The family members also gave them

consultation when the informants encountered the problems and they tried to prevent the informants from being tense.

The seven informants realized that their HIV infection would lead them to the suffering stemming from the illnesses and death. That resulted in the feeling of discouragement among the informants sometimes. However, they perceived that they got consolation by their family members who told them not to be concerned about working, earnings, illnesses and death. The family members also emphasized that they would always stand by to give love and take care of the informants as shown by the following statements:

- "... When my mom knew I was infected, she consoled me and told me to put aside the disease.... She told me not to work and be sad." (Bua)
- "... My elder sister told me not to be serious and said everyone even rich people must die. So why worry? That brought tears to my eyes at that time" (Pen)
- "... My elder sister told me not to be sorry. I'm not the only one who was HIV- positive. It won't turn out worse if I take very good care of myself. ... She's talked with me in kind words and she hasn't abused me. She said that I still have mother and father whom I can live with. She told me to stay together with other sisters and brothers. Mom and Dad love us equally. I don't need to feel sorry. If anything happens, we still have relatives." (Lar)
- "... They told me that HIV- patients didn't die of HIV easily. Even though I have been infected for several years, I still don't have any wrong symptoms.... They's stood by me to give me the will power. Those who died of HIV because they didn't take care of themselves and weren't aware of taking good food." (Karn)
- ".. She always consoles me and tells me not to be pessimistic. Don't think too long, just think of the present and don't look back what has been passed. Think of today only because tomorrow is the future. She doesn't want me to be too serious." (Tim)

- "... I think it already passed. And they've also gave me will power by telling me not to think about the death. My dad also said if I fall sick, he would take me to the hospital... they're consoled me and told me not think a lot, they're still beside me." (Ked)
- "... He's consoled me and said it's all right and I won't die easily. I can live with him even though I'm HIV-positive. My health is still strong." (Pin)

Five informants perceived that they were forgiven and not aggravated by family members. In some cases, one male informant was forgiven though he transmitted HIV to his wife and baby, one informant felt proud of being forgiven even though his behaviors in the past were not good. These forgivenesses were expressed by which the family members kept talking nicely with the informants. The informants were not deserted or driven away. Also four informants indicated that their family members did not aggravate them for being HIV positive. In these four informants, one female informant indicated that at the first time when her father knew about her HIV-infected, he frequently cursed and aggravated her and after he knew that repeating this matter had discouraged her, he became treated her good. The forgiving and not aggravating from family members is shown by the following interviews.

<sup>&</sup>quot;... I told my wife that I'm sorry for being HIV-positive and transmit the disease to her and our child. She said nothing but told me not to feel sorry. It already happened. My wife is very strong. She didn't cry and said we must be patient. Don't feel sorry." (Roen)

<sup>&</sup>quot;... My mom didn't aggravate me. She forgave me for what I've done and talked to me normally. She didn't disregard me. That means she forgave me by not aggravating, not repeating and not driving me away.... I've done a lot of bad things but she still forgave me and took care of me." (Ek)

- "... I feel proud that my mother didn't abuse and aggravate me for being HIV-positive. Nothing affected my mind." (Bua)
- "... He didn't blame me. That means the will power for me. My dad used to curse me for being infected. He said he had warned me to be careful but I ignored his warning. He frequently cursed and aggravated me. It already happened. Repeating this matter had discouraged me. Eventually, he treated me well. I've felt nothing so far. I just don't want others to aggravate me. I know I made a mistake." (Karn)

"He didn't aggravate me. I feel glad that he didn't blame me that I have married with AIDS person." (Ked)

The two informants perceived that the sympathy they got from their family members stemmed from the consultation of their family members when encountering problems as shown by the following interviews:

- "... When I've got any problems, I can consult with him. Or when I'm at home, I want him to give me advice whenever I face the problems or some symptoms of illness appear. It's the will power that I get from him." (Rut)
- "... When I have problems, he'll talk with me and help me solve the problems. This is called will power, isn't? Whenever I have problems, he'll tell me not to be worried as the problems can be solved....They say the problems could be gradually solved. That can encouraged me." (Noy)

In addition, three informants indicated that their family members always tried to relieve their stress. They say their families always observed and asked them when seeing them look serious so that their families can suddenly help them. The family members also put an emphasis on care taking to prevent them from tension by offering help when the informants faced the problems. They tried to find topics to talk, joke,

play riddle games, sing with the informants and provide some books for the informants. The statements about relieving their stress presented as follows:

"When I'm serious, they will ask what happens to me or what they can help. If they can, they're ready to help me. They don't want me to be serious. They keep me cheerful by joking with me.... My husband is quite childish. He rarely gets stressed or keeps thinking about the problems. We won't mention about the matters that made me worried. My child and husband sometimes play with me. We play riddles or sing songs together." (Noy)

- "... Don't make me get stressed. If there's nothing wrong and I don't get stressed, there won't be any problem. I can eat regularly and have normal life.... The most important thing is will power. Other things are meaningless. Will power can get rid of my stress." (Dui)
- "... My mom often buys me books. She knows I love reading. Sometimes she took me to borrow some books at the shop. She's afraid I'll be serious and unhappy. (Tim)

#### **Showing No Disgust**

The eight informants told that they got will power (kumlungjai) from the family members who showed that they did not disliked people with HIV/AIDS by persuading them to go out. Also, when they had a meal together, their family members shared the cutlery on the table with the informants. The informants' clothes were washed together with other family members' or even the members let the informants wash clothes for other members. One of these informants told that sometimes her mother lied down on her bed. Moreover, one told that his younger brother helped carrying him in his arms when the later were not able to walk himself as shown by the following interviews.

- "... She didn't show any signs of disgust. She touched my body and my arms, asked me how was I. When I fell ill, she helped me to put on clothes... She didn't fear or show any disgust. She's done everything for me. That meets my needs." (Kam)
- "...They persuaded me to go out without an expression of disgust. They didn't hate me. That's the encouragement for me. When we had a meal together, we ate together and they didn't separate the spoons or other things. Our clothes have been washed together and sometimes they let me wash their clothes." (Karn)
- "... They didn't dislike me. When we have a meal together, they share everything with me without any signs of dislike." (Bua)
- "... We've eaten on the same table and they've talked with me nicely without a show of dislike since they knew that I was infected. It's the warmth that I get from my brother." (Lar)
- "... When we've had a meal together, they haven't shown that they didn't want me to eat with them. I've felt very glad that they didn't dislike me."
  (Ked)
- "... They didn't disgust me. Sometimes my mom has washed my clothes while I was sick and unable to move.... And she used to lie down on my bed with me to watch the T.V." (Rut)
- "... I told my mom not to wash my clothes as I got skin rashes, but my mom said my clothes didn't transmit the disease to her and she's already old and must die sooner or later." (Pin)
- "... We always eat together. Sometimes my dad took food from my bowl and said that he wasn't afraid of being infected from me and he's already old and must die sooner or later.... Sometimes my younger brother wanted to take me for a walk, I said I couldn't walk too long. He suddenly carried me in his arms to take me for a walk. I also told him to wear a pair of gloves as I was afraid he might be infected, but he didn't." (Roen)

#### **Psychological Support**

The informants indicated that they need psychological support from their family caregivers. They need an understanding and care as normal people. Also, they need close care and touch as follows:

#### Understanding

The informants described that they need understanding from their family members. They want their families to understand their emotions, feeling and behaviors. They also want them to understand their suffering and their needs as well. The informants wanted them to have understanding and knowledge about AIDS, treatment of AIDS patients and caring for HIV/AIDS patients.

One of the informants told that he needed his mother to understand his sorrow and feelings after having known that he was HIV positive as shown by the following interview:

"... I need my mother to understand how I feel, how I am and what happened to me. I want her to know this.... Actually, the most important person whom I want to tell is my mother. I want her to understand how I feel and how my health is, I've got something in my body that is different from other people. I'm not as the same as others." (Ek)

Three informants needed their family members to understand their own behaviors and actions even though these behaviors might make some family members feel unhappy or might be inappropriate such as hanging around, drinking, smoking and taking drugs. The informants want their family members not to judge or regard these behaviors as mistakes or bad thing as shown by the following interviews:

- "... I want them to understand me for everything I've done. Sometimes it might make them unhappy but I want them to understand that I did the right thing. I want them to let me do things that make me happy." (Lar)
- "... I want them to ignore what I've done. Everything I did was my need and thought. I wanted them to think that I have had the right decision on what I wanted to do." (Karn)
- "... I want them to understand so they won't blame me and set me free. I'm already infected with AIDS so I want to spend the last moment of my life to the fullest. My mom said I ignored her words. I had destroyed myself by drinking, smoking, taking drugs and any other things. In my family's eyes, they saw me as a bad people. I did every bad thing because I wanted to forget. I want to reap the happiness before I die. I was born just one time, so I have to live my lifetime to the fullest. If I die, I feel nothing; I can't see, can't hear, can't meet and can't touch. Actually, I want someone to understand me and the reason why I had misbehaved because I'm infected with AIDS. I wanted them to understand, set me free and let me do anything I wanted if that didn't cause any troubles. Everybody saw me as a bad guy. Is the word 'bad'' too violent? Everybody hated me even my mother, father and brothers didn't liked me. But in other words, I was wrong. I didn't take care of myself. I'd destroyed myself. If I'd controlled my behavior and taken good care of myself, any wrong symptoms might not have been happened to me. If they had understood me at that time, I would not have done that. I should have taken good care of myself as I'm doing today." (Ek)

The three informants need their family members to know that they might have to change some lifestyles in order to prevent their health from developing worse after they were infected with HIV/AIDS. They also want their family members to know how to prevent the spread of the disease.

"... I need their understanding. They're supposed to understand me that I've got the disease inside my body. It makes me different from other normal people. Normal people can do and eat anything because they don't have to be worried about the consequences. But for those who are sick or HIV- infected people, they have to remind themselves that they're

HIV- infected people, they can't overeat. Eating for getting rid of hunger is enough for people like me. Eating too much can be harmful.... They should understand I'm infected with the disease. Therefore, I've got something different from others. They must understand that I have to change some of my behaviors. (Noy)

- "... I need them to take care of my health. They should know what kinds of food are suitable for HIV- infected patients. Some misbelieve that HIV infected patients should take fish that have scales and must not drink coconut milk. I can't change their misbelief; in fact, HIV- infected people can eat every kinds of food. They should understand this. I'm aware what kinds of food are not good for me." (Rut)
- "... They should understand how to treat me as a HIV/AIDS patient. People like me are always worried if we'll transmit the disease to other people. So let's meet at half way. If one day I have tuberculosis, other people will never get infected with my disease. Or if I have skin rashes, they should know that they can wear gloves when taking care of me." (Dui)

The two informants need their family members to understand their illnesses and treatment of the symptoms. They also want their family members to understand the symptoms stemming from the illnesses due to HIV/AIDS and they want them to know the methods of care taking or dealing with the symptoms as shown by the following interviews:

- "... The most important thing I need is understanding. I want them to know that when I have a fever and get stiff, it's hard for me to move. So they must ask whether I need medicines or not. My mother would ask me whether I need to take pills. If I need, I would tell her and she would bring them to me." (Ked)
- "... I want them to take care of me. I want them to understand how to treat me If I fall ill or have a fever. I often have a stomachache so I want them to know how to cure my symptoms so that I can ask for their help." (Rut)

## Treating as Normal People

The four informants described that they need not to be treated by family members as HIV-infected patients or be viewed as a carrier of disease. Nor do they need to be aggravated or repeated on the HIV/AIDS infection by preventing them from some activities such as going out, eating some food and expressing dislike. They need to join the family activities as normal people. They want to help doing the housework while they were still healthy and able to do any activities or works. They do not want to be treated as patients as shown by the following interviews.

- "... I want them to see me as normal like other people. I want them to look at me as if I weren't infected. I feel they've adjusted themselves to me because I have HIV. But I don't want them to look at me that way. They've treated me as an AIDS patient even though my health hasn't get that serious. I'm still normal like them. I want them to treat, talk and do other things with me as a normal person, not an infected person." (Noy)
- "... I want them to treat, see me as other normal people and eat with me as usual like other families who eat and live together without separation. But now it seems that they see me as a strange thing because I'm infected with AIDS. I don't like them to view me as an AIDS patient with AIDS. I want them to see me as a normal person." (Rut)
- "... Please treat me as usual as a normal person! I'm not special. Don't treat me particularly! Don't look who I am! (Dui)
- "... I don't want them to say that I'm different from them and don't like them to prevent me from doing anything. I need them to treat me as usual." (Lar)

#### Maintaining Close Care and Touch

All informants have had records of illnesses or some experienced in taking care of other AIDS people, resulting that they needed close care and touch when they were infected. The three informants indicated that the family members should visit

them at the bedside when they fell ill or were not able to help themselves, they do not want to be looked at from a distance. When taking care of them, the family members should touch them, and give the warmth to them as shown by the following interviews:

- "...I need both will power(kumlungjai) and nice practice from my family. It's not only the will power they should give me but also touching me or talking with me. if they talk to me from a distance, I'm not touched by their practice like that.... when I'm sick and can't move or do anything by myself, they should take care of me closely like cleaning my body, touching my arms or holding my hands....Or when my condition gets worse, they should touch me or massage me." (Karn)
- "... I want them to be close to me. If I have a fever, they should clean my body so the fever might go down. They should to take turns to take care of me all the time. I need their close treatment." (Lar)
- "... It's not that they come to visit me but say only few greeting words like 'how're you doing?' or 'have lunch yet?' I don't want that. I want them to move towards me to hold my hands and ask such questions showing their concern or massage me. I don't want them to stand at the house door and ask me in a loud voice from such a distance. They should move towards to touch me. I think I can feel from their touch that they're really concerned about me, can take care of me and can encourage me. It's meaningless if they show their concern from a distance" (Noy)

#### Summary

Caring is the first theme generated from the descriptions of the people living with HIV/AIDS (PLWAs). Caring is the care provided in the forms of encouragement, helping and supporting mentally. Caring shown through the will power (kumlungjai) and psychological support. The will power (kumlungjai) is the meaning of family caregiving as perceived by PLWAs which stemmed from receiving of love, concern, sympathy and showing no disgust. Meanwhile, the psychological support is the need

of family caregiving that based on understanding, treating as normal people and maintaining close care and touch.

# Theme 2: Care Received from Family Members

The results of this study shows that the informants described their family caregiving to the care received from family members as the self-devotion of family members or the caregiving due to duty. The self-devotion of family members to the informants came from the bond of family ties, resulting in the changes of family member's lifestyles so as willingness to take care of the infected people. However, the informants sometimes felt that the care they have got exceeds their needs. Meanwhile, the caregiving due to duty was due to the necessity to do. As a result, the informants were treated coldly and distantly and sometimes they got an expression of disgust from their family members.

Table 3 : Categories and Subcategories for the Theme: Care Received from Family Members

CATEGORIES AND SUBCATEGORIES	THEME
Self-Devotion of Family Members	
The Bond of Family Ties	
Lifestyles Change for Giving Care	
Giving Care with Willingness	
Giving Excessive Care	CARE RECEIVED FROM
The Caregiving due to Duty	FAMILY MEMBERS
The Necessity for Care	
Distant Caregiving	
Expression of Disgust	

### Self-Devotion of Family Members

Self-devotion of family members refers to the actions of giving time, energy to the informants according to the constant strong love for informants. The self-devotion of family members was developed from the bond of family ties, lifestyles change in order to take care of the informants, giving care with willingness, and giving excessive care. Those informants who were still single indicated they got the devoted care from their mothers whereas those married ones got the devoted care from their spouses.

### The Bond of Family Ties

It was the family tie that combined the members together such as the bond between mother and children, the bond between husband and wife and the bond between brothers or sisters and relatives. This bond, as a result, created the help of taking care of each other whenever the members were sick and do everything eventhough the dirty tasks. That also made the informants realize that they were a part of the family. The informants described that the care received from their family members was the responsibility and conscience, and the family members would take care of other members who faced difficulties and needed help as shown by the following interviews:

- "... I think there must be something that made them to look after me and do everything for me. In my opinion, there are only husbands and wives or mothers and children who can do anything for each other because these people have bond that ties them together." (Noy)
- "...My mother does everything for me...that because we are mother and child." (Ked)
- "... I think people who are willing to take care of me must be connected with me in some ways. If they only know me, they wouldn't take of me. Like my father and mother, both of them have been taking care of me as they are my parents and we have a bond that ties us. Even my husband, he has been looking after me after getting married with me, but before that, he was just an outsider, just a boyfriend." (Rut)
- "...Truly speaking, who dares to discard my feces if they are not my mother or my wife? Even my brothers and sisters, they dare not to do that for me. Am I right? I think those who can do this dirty task for the other must be those who have a marital relationship like husband and wife." (Dui)
- "...Because I'm sister in law, the bond in the family ties us together. It's this bond of kinship that makes me feel that they must take care of me. Others who are not in our family might not treat me like them. They do that because I'm a part of the family." (Pin)

"... When I'm sick, who will take care of me? If there's someone who looks after me, would he treat me like a husband does for his wife? It's impossible for people who are not close to me to take care of me." (Bua)

# Lifestyles Change for Giving Care

The three informants perceived that their family members have changed their lifestyles to take care of them. For example, an informant said that his mother would cook and eat food which would be less spicy as he cannot eat spicy food. Also, two informents said their family members would stop eating and cooking food, which were believed "harmful" for him. Some family members of an informant have changed their bedtime by going to bed later than the informant. In addition, the mother of an informant has been at his bedsides in order to take care of him during nighttime as shown by the following interviews:

- "... In the past, my mom slept on upstair but now she has moved her mattress to sleep beside me so that she can take care of me at night and I can call her if I need help .... I can't eat spicy or salty food anymore but my mom had cooked spicy food. So my mom has to cook and eat less spicy food like me. She has to adjust herself to me ." (Leur)
- "... My mother doesn't go to work as she's afraid that I'll stay alone and lonely." (Ked)
- "...Luang Poh (an old monk) at a nearby temple told me not to eat eels as they were not suitable for people with AIDS and will make my health worse. He also warned me against grilled pork intestines, chicken, beef and buffalo meat. So no one in my family eats them although we used to like them. When Luang Poh told us to stop eating them, we followed his words.... All in my family wait until I sleep, so they can go to bed." (Roen)

Two informants told that their family members have changed the way of talking with the informants after knowing that they were HIV-infected. They would use kind words and would not shout or use rude words to the informants as shown by the following interviews:

- "... My mom won't speak in a loud voice. If I make a mistake, she will talk with me slowly as she realizes that I'm quite sensitive and can't tolerate something violent. If there is something that affects my mind, I'll get upset for a few days." (Tim)
- "... My dad used to speak with me in harsh words as he didn't think that might harm my mind, but now he's changed. He would not be rude to me or make me discouraged. I regard it as a show of caring." (Noy)

# Giving Care with Willingness

The seven informants experienced that they have been willingly taken care by their family members. The characteristics of giving care with willingness were immediate care and showing no signs of anger and tired. The members would quickly take care of the informants even though their illnesses were not serious. The family members would patiently treat the informants without showing any signs of anger and tiredness. They would do anything for the informants willingly as shown by the following interviews:

- "... My mom willingly does everything for me. Nobody wants to take care for me but my mom is willing to do it. She never disappoints me. Everything I want, she will find to please me." (Ek)
- "... She's concerned about me and willing to take care of me when I have fever." (Kam)
- "... When I'm ill and need some help, my husband will immediately come to see me and sometimes give me a massage to relieve my pains if I get pains on my arms and legs. He doesn't regard as a small matter as he's

willing to look after me. If I ask for his help, he will quickly do it for me." (Noy)

- "... If I'm sick, who will take care of me willingly like my mother and wife? Without them, it's impossible for other people to treat me well and willingly because they have to discard my feces." (Dui)
- "... I feel proud that they take care of me and do everything for me. I don't have to do anything and they never get mad at me and are very patient since they knew I'm infected. Although I can't be cured from this disease, I'm still proud as they treat me very well.... I sometimes think that my father, mother and wife get bored of taking care of me, but they don't." (Roen)
- "... They told me that I'm not in danger. My father and mother aren't afraid of me but said that they want to die for me.... Sometimes I can't move, so I ask my mom to take the medicines for me, she takes them for me. She's very nice to me. She washes my clothes even my underwear. She always tries to please me." (Ked)
- "... My mom tries to seek food for me to eat. Whatever I want to eat, she will buy for me." (Rut)

With regards to providing care willingly, one informant told that everyone in his family has willingly taken care of him for nothing. The care is not for money but it's happiness that they take care of the patient as shown by the following statement:

"... The way that my family has treated me, I can say that it's not for money but it's rather a happiness. The students in the hospital took care of me because it's part of their study to graduate and they want wages but my family and my wife take care of me because of love and sympathy. It's not that they wash my body and I'll give them scores or money but it's their responsibility. What they get is the happiness to see their beloved clean. It's their happiness to take care of me." (Dui)

However, two male informants who received care from their wives felt that although their wives have taken care of them with willingness, they sometimes felt that their wives might feel bothered and serious. One informant told that sometimes

his wife complained when she had to wake up at night in order to fill a jar of water for him as he must drink a lot of water during nighttime. Another one informant told that his wife often showed her stress and complained but he did not know the reason why his wife got stressed.

- "... She's always grumbling. When I have a diarrhea at night, I've to call her and that makes her complain but she still helps me. Sometimes she complains that I drink much water and she has to fill a few jars of water for me at night, but she still does it for me." (Roen)
  - "... She claims that she's stressed but I have no idea what makes her stressed." (Dui)

Furthermore, although two informants who had his mother or wife taking care of them felt that their mother or wife has taken care of them with willingness but his mother or wife had changed some ways of living together with the informants. For example, the informants would be prevented from using the same cutlery, sleeping in the same bedroom and using the same bathrooms with other members in the families. In addition, one informants indicated that they were ordered by his mother not to be close to his younger sisters even though they had the close relationship before. The informants attributed this expression to the fear of being infected as they lacked the knowledge and understanding about AIDS. Moreover, the informants were not certain about the infection and sometimes agreed with the care of their family members even though that made them feel sorry as shown by the following interviews:

<sup>&</sup>quot;... We share the same set of bowls and dishes except soup spoons as a preventive way. I don't say anything about this matter but I sometimes feel sad that I'm different from other people. There is a distance between my wife and me. Our relation has changed because of me." (Kam)

"... We don't use the same sets of cutlery like bowls, dishes, glasses, spoons and so on and we don't eat together anymore. I eat alone and sleep alone. I think they dislike me as they're afraid of being infected from me. My mom also tells my younger sister not to play with me. Moreover, they tell me not to use the same bathrooms with them. I understand that they're afraid of being infected from me... My mother will wear two or three pairs of gloves and her face looks unpleasant when she has to empty my spittoon. Or if I cough, she would immediately get away from me." (Ek)

# Giving Excessive Care

The four informants felt that they have got more care from the family than they needed or expected. The family members showed their excessive care by going to visit the informants even though they were not seriously ill. They tried to please the patients so much that the informants were afraid that they might bother their families too much. In addition, the informants wanted to help themselves first if they could do it. The informants indicated the care was sometimes unnecessary as they can help themselves.

- "...I'm afraid that I might bother them too much. If I tell that I need their help, they would suddenly do it for me, but it's too much. They help me more than I want." (Kam)
- "... I have got more than I expected. I think I'm not supposed to get much care but my father and mother have tried to make me happy." (Roen)
- "... I feel bad sometimes as I think it's too much for me. When I have a slight fever, my relatives come to visit me in a big group. It's too much, though I feel good that they give me will power, attention care and concern.... I think I'm all right and in good health and also can help myself. I realize their care is an will power for me to make me feel better but I'm still healthy, it's not necessary for them to be worried about me too much.... If my condition gets so terrible that I am bedridden, that's the time they're supposed to come to take good care of me. I try to keep myself healthy as I don't want to bother them to visit me. Sometimes I just take a short nap, they think that I'm seriously ill. I'm not talkative and don't speak, they assume that I'm sick and call other relatives to

visit me. They also buy me a lot of food to visit. I think it's too much."
(Leur)

"... They came to watch over me. My husband's relatives just came to visit me a few days ago. But I wasn't as seriously ill as they thought, so it's not necessary for them to come to watch over me." (Noy)

However, one of the informants thought that she caused troubles to her mother if her mother had to take care of her, as shown by the following interview:

"... My mother has to take care of and please me all the time. That makes me feel bad. It makes me think that my infection causes troubles to my mother that she must look after me more than before. In the past, they didn't take care me much like now when I wasn't infected." (Lar)

One informant told that her family members have been so much care that she felt irritated.

"... When we have a meal, they always warn me against food that might be harmful to me even though I'm all right. They suggest that I avoid or eat less. It makes me different from other people. I get the message but they still warn me all the time. Sometimes I get annoyed by their warnings. Warning just one time is enough." (Karn)

# The Caregiving due to Duty

The family members of the informants were mostly men including elder, younger brothers and relatives. The care provided to the informants was dutiful; that is they took care of the informants because of the necessity for care. Therefore, the care was distant and an expression of disgust could be seen.

## The Necessity for Care

Four informants perceived that their family members had to take care of them because it was their duty to look after the members who were sick or needed help. Combined with the fact that the informants did not have other people to depend on, the family members felt sympathized and could not desert the informants. However, that made the informants think whether they were taken care by their families with willingness or not.

- "... It's because of duty. I don't know whether they are willing to take care of me." (Ek)
- "... Some are not good, they're unwilling to help me or be forced to help me because of the responsibility." (Lar)
- "...It's something like he takes care of me because of duty. If I'm not his younger brother, will he take care of me? He looks after me as a brother. I understand the point because I have no one else except my elder brother and his wife. They also don't have anybody except me. It's duty that makes them look after me." (Dui)
- "...It's because I have nobody except her (elder sister). My father was died and also my mother was died... She take care of me because I have no body." (Pen)

# **Distant Caregiving**

Five informants perceived that they got distant care from their elder, younger brothers and other relatives. The care was shown in forms of helping providing the informants with necessities and food and visiting the informants from a distance rather than taking care by themselves. When the informants sometimes asked for advice or help in doing some housework, they would get a disregard. Moreover, some

informants were ignored by their family members as shown by the following statements:

- "... When I'm sick, the only thing they do is to ask about my condition. That's all. My elder brother didn't cared about me. When I asked him whether I should take anti-viral drugs, he said he didn't know and didn't help me make a decision." (Dui)
- "... My father didn't take care of me. Normally, we hardly talk with each other. I don't want care from my father because he's that type of person. When I recovered at a hospital, he came to visit me but didn't do anything, just looked at me, nor touch me." (Ek)
- "... Though I have a younger brother, he doesn't help me much. He helps me occasionally. He just asks me how I am. Sometimes he gave me some food or snacks. That's all he has done." (Kam)
- "... My aunts always ask about my health when I'm sick and have to go to see a doctor. It's just something like asking, but no action." (Rut)
- "... Sometimes, my younger brother took care of me but he didn't intend to do that. Because I asked him for doing that. As I told him, he did but not willingly. That's because he's so young." (Karn)

#### **Expression of Disgust**

Three informants said that the appearance of some symptoms of illnesses such as skin sores, rash, cough, tuberculosis and fungus, could be important factors that cause the family members show their disgust towards them because of the fear of the spread of the disease as shown by the following statements:

"... When I was at the hospital, they went to visit me there but they just stood and looked at me from the foot of the bed because I had a cough.... If I have sores all over my body, they would not come close to me." (Ek)

"... I used to have tuberculosis which is a communicable disease and I had fungus infection in my mouth and looked completely bad. It seemed that my elder brother and his wife didn't want to get close to me or touch me as they were afraid that they might get the disease from me. Or if they must touch my body, they acted like they were forced to touch it." (Dui)

"... when my aunt knew that I had skin rashes, she wouldn't like to contact me." (Karn)

### **Summary**

The care received from family members is the second theme emerged from the study. Care received from family members revealed the types of care provided by family members. This care could be divided into the self-devotion of family members or the caregiving due to duty. The self-devotion of family members to PLWAs came from the bond of family ties, in the changes of family member's lifestyles so as to take care of PLWAs willingly and sometimes giving excessive care. Meanwhile, the caregiving due to duty was due to the necessity to do, distant caregiving and expression of disgust.

### Theme 3: Lengthening Life

The informants described the meaning, the care received from their family caregivers, and the needs of family caregiving as lengthening life. They indicated the essentials for long life as receiving and needs of family caregiving, and expressed the needs of family caregiving for lengthening life as supporting for survival. For the

essentials for long life, the informants realized that the family caregiving was receiving and needs of absolutely necessary for life, and receiving the strong will for fighting. The informants described the support for survival as receiving care for promoting and protecting their health, receiving and need of supporting for their dependence, receiving the social care, and the needs of preparing for their dying from their family members as shown in table 4

Table 4: Categories and Subcategories for the Theme: Lengthening Life

CATEGORIES AND SUBCATEGORIES	THEME
The Essentials for Long Life	
Absolutely Necessary for Life	
Strong Will for Fighting	
Supporting for Survival	LENGTHENING
Caregiving for Promoting and Protecting Health	LIFE
Supporting for Dependent Care	
Supporting for Social Care	
Preparing for Dying.	

## The Essentials for Long Life

The informants described that care received from their families was essential for them to live. Family care was absolutely necessary for their life. The family caregiving was necessary for their life because they could not lack of it and must

depend on support and assistance from their family members. Moreover, the informants received the strong will for fighting from their family members since the strong will could help them feel courage to fight with the illnesses threatening them.

# Absolutely Necessary for Life

The eight informants gave opinions that they cannot lack of family care. They must depend on the family members. They told that without the family care, they might not have had a desire to live. The families provided everything for them, encouraged them to live longer, prevented them from illnesses, tried to make them happy, helped them to recover from the illnesses. Receiving the support and assistance from family could lengthen their life. The family care was like a power or drug that could prevent them from recurrent illnesses and lengthen their life as shown by the following interviews:

- "... My wife has done everything for me. Without her, I can't live, I should have died long time ago. If I didn't have her, my life would have been getting worse and worse because I didn't have a desire to do anything. I can't help myself, I must depend on her." (Kam)
- "... he does everything to keep me alive and live as long as possible and to prevent me from illnesses." (Tim)
- "... I think that he's treated me nice as to make me happy not sad. Unhappiness and stress could make me die early." (Pen)
- "... If I don't have my parents and brothers/sisters to take care of me, I can't live. If I have nobody to look after or to give me advice, I could have not lived so far. My neighbors don't not take care of me like my brothers/sisters do." (Lar)

- "... If I have no one to take of me, my life must be worse and I can't live. If I didn't have my mother, who would take care of my food and my mind? Care is the most important thing that helps me recover. (Ek)
  - "... I think their care and treatment could make my life longer." (Karn)
- "... If I have nobody to take care of me, my health must be worse or even I might die because when I'm sick and don't have any medicines like paracetamol and nobody is at horne, who will buy them for me? So if I have someone to take care of me, I can ask him to buy paracetamol for me." (Noy)
- "... I'm the first infected person in the village but other people wonder why I'm still alive. They think that my family must have magic drugs that keep me alive. I think the family keeps me alive. Other infected people in the village have died of the disease because their families did not have time to take care of them." (Rut)

## Strong Will for Fighting

The eight informants perceived that care received from their family members encouraged them to have a strong will to deal with several problems such as fighting with the conditions of infection and illness and fighting with the problems about work, and also promote the informants to take care of themselves for their families. Among these informants, there were three who stated that suffering from the terrible illnesses made them discouraged and think of only death. However, the care, support and assistance provided by their families could make them have energy and a strong will to fight with the disease as shown by the following interviews:

<sup>&</sup>quot;... Their treatment has given me a will to fight further. If they didn't treat me good, I would have died long time ago. They've taken good care of me and that encourages me to stay alive until now." (Tim)

<sup>&</sup>quot;... Their care and treatment give me a power to fight against the disease and other problems. Everything I do seems to be powerful. But if nobody encourages me, I would be discouraged to do anything and

won't get success. Encouragement drives me to continue fighting and doing everything good." (Rut)

- "... They've done everything for me to fight with the disease because I'm depressed with my disease. They told me not to fear it. Their words have encouraged me... If they leave me, I might do something stupid like drinking or hanging out. But they live with me though it's their duty, I regard it as an encouragement that keeps me alive and drives me to take good care of myself for them, for my family. I think I still have my family who stands by me." (Dui)
- "... My father together with my husband's brothers has encouraged me. That makes me happy and think of them that they've treated me well. They're nice to me, still encourage me and love me. I want to live with them forever. (Noy)
- "... I try to eat a lot to make myself healthy and to get fatter. Their encouragement makes me feel better. If there're any good medicines coming out, I'll try to take them." (Ked)
- "... It make me fight, endure with everything. They provided strong will to fight, made me alive. Sometimes I wanted to die because of the suffering disease but my son encouraged me. When I was ill, he told me to see the doctor. So, he is my will-power." (Pin)
- "... I feel discouraged sometimes and I don't care if I die but my mother doesn't want me to say that stupid word. I can feel that she doesn't want me to die and she's still concerned about me. Her words encourage me to live." (Karn)
- "... I wanted to die when I were terribly ill because of this disease, but the help from my brothers has aroused my fighting spirit. Their help gave me a will to fight and I must try to help myself. They don't want me to die so I must continue fighting to live longer. I try to help myself to keep myself healthy." (Leur)

Moreover, an informant felt that they caused their parents troubles as they must take care of them; therefore, the care received from parents would be like a power that encourages them to recover from the illnesses and try to help themselves as

much as they can to minimize the bothers caused to their parents as shown by the following interview:

"... They're like the power that makes me to stay alive and not to commit a sin. They support me to recover from the disease and to help myself. I take a pity on them that I don't want to bother them." (Ek)

## Supporting for Survival

Supporting for survival is the needs of family caregiving and the care that family members provided for people living with HIV/AIDS to prolong life. In this study, the informants described the family care to sustain their lives involves receiving caregiving for promoting and protecting health, receiving and needs of supporting for dependent care, receiving supporting for social care, and needs of preparing for dying.

### Caregiving for Promoting and Protecting Health

The informants told about the care received from family members for promoting and protecting their health by saying that the members would take care of their work, nutrition, sleep and rest, care about environment, care to prevent from illness, observe and ask their conditions, care for controlling the symptoms, and seek for treatment.

Three informants told that their family members would warn or stop them from doing hard works after knowing that they were infected with HIV. Among those three informants, one stated that her family members would feel concerned as she was not as strong as before. Meanwhile, the remaining two informants indicated that their

family members still allowed them to work only if it was not hard and they must take some rests if they felt tired as shown by the following statements:

- "... They don't let me do hard works like harvesting rice crops or farming as before. They're afraid that my health will be weak and I might fall ill as I'm not as strong as before." (Lar)
- "... My parents don't let me to do hard work. Since I knew that I'm infected, I've not walked past the rice paddy. I was a farmer. But since I infected, I've been there a few times, but not to do farming. I just helped draw the water and gave some snacks to other farmers there." (Karn)
- "... They don't force me to work but if I have time or anything I can help, I would go to help them. My father told me that I can go to work but I should take a rest if I get tired." (Rut)

With regards to the food, six informants told that their family members would warn them to stop or avoid eating food believed harmful or bad for their health like preserved, uncooked food, some vegetables and some meats, etc. They were also told not to eat too much or too little as shown by the following statements:

- "... I like eating bamboo shoots but they make me feel pains on my legs. So my mother prevents me from eating bamboo shoots, pickles, preserved vegetables and other things. She always warns me not to eat these food." (Ked)
- "... They always warn me against eating some food, saying that it might make the symptoms appear. They don't let me eat raw mince but cook it. We used to like eating raw mince, but since they knew I'm infected, they would cook it first." (Karn)
- "... They do not allowed me to eat preserved food. Most food I can eat includes pork and vegetables. But there're some vegetables I can't eat like Pak Ra or Cha om (Acacia), Kra Pi (Shrimp paste) and Pla Raa (preserved fish) are taboo for me as well." (Tim)
- "... My father blamed me when seeing me eating harmful food and asked if I don't love myself anymore. And if I die, whom my child will live with? My father asked me such a question in a loud voice." (Pin)

- "... I can share food with my family members except some dishes they believe are harmful to me. They would tell me to avoid those dishes."
  (Bua)
- "... My husband takes care of food that I should eat. I don't like fresh green vegetables because they smell bad but he tells me to eat. I try to eat some but can't bear the smell and sometimes spit it out. But he still pushes me to eat, saying that fresh vegetables are rich of vitamins and nutritious. And if I don't like fresh ones, he would cook them... My husband would push me to eat some when I don't eat anything. But because I have a peptic ulcer, if I don't eat, I fear that I might have other complications." (Rut)

With regard to taking rest or sleeping, three informants told that their family members would warn them to have enough rest or sleep as shown by the following interviews:

- "... He always tells me that it's time for me to sleep even though it's just 7 o'clock in the evening. He wants me to have enough rest and doesn't like me to watch T.V., saying that I might be addicted to it and would stay late at night." (Tim)
- "... If I stay late at night to iron clothes and watch T.V., he would tell me to go to bed as it would be bad for my health. He always warns me about my health." (Karn)
- "... Sometime I get dizzy, they tell me to stop and take a rest." (Leur)

For the environmental care, three informants told that their family members took care of the cleanness of the house and bedclothes including pillows, mosquito nets and warned them to stay in an open-air area as shown by the following statements:

<sup>&</sup>quot;... My nephews help me clean up the house when I'm ill. They help sweep and wipe the house." (Leur)

- "... My husband take care of me, help me. He tries to do everything for me if he can such as washing the bedclothes, if he can he will do it."
  (Rut)
- "... They take care of the cleanness and tell me to stay in an open-air area. They also tell me to clean my bed, pillow and mosquito net by having them aired in the sun. If I don't, they would do it for me. They don't let me sweep the floor as they're afraid that I might be allergic to dusts and my mother would sweep it. But if I insist on sweeping, they would tell me to take a bath after finishing the job." (Karn)

Three informants perceived that they were treated to prevent them from any illnesses. The family members would not allow them to go to crowded places, prevent them from getting wet from the rains, warning them to wear coats if it was cold outside, stopping them to go out at night to avoid the cold and dewy weather as shown by the following statements:

- "... If it rains and I get wet, I'll be sick and have a fever or cold for several days. It's hard for me to recover. My father would ask what I want and he would get it for me. He doesn't want me to go outdoors as I might get wet from the rains. My mother is more concerned about me. Sometime, I get off the car and it rains, she would open an umbrella and run after me to protect me from the raindrops." (Ked)
- "... If I'm sick, they would tell me to put on a coat or something like that.

  Or if I cough, they would tell me to take care of myself." (Dui)
- "... They don't like me to go out at night, saying that it's crowded. It's also cold and dewy at night that could make me ill." (Karn)

Observing and asking the informants' conditions, four informants indicated that their family members would observe the changes of their conditions and behaviors and if their conditions changed, they would ask them about the conditions as shown by the following statements:

- "... She (mother) takes care of my health. If she notices that I look sluggish or a bit strange, she would keep asking about my condition. If I have a headache, she would know that. And if I look different from yesterday, she would immediately ask what happens to me." (Tim)
- "... If I look thinner, they would observe it and ask me about my condition. And my mother keeps asking me and warns me about going out and sleeping." (Ek)
- "... If I'm sick like having a stomachache or a fever, he would keep asking me all the time how is my condition." (Rut)
- "... My father always looks after me. If I'm sick, he will wake me up because he doesn't want me to sleep too long as he thinks that I won't wake up anymore. He keeps watching over me." (Noy)

Providing care of taking medicines in order to control the disease, five informants stated that they received care from family members in order to control the development of disease by which the members would instruct them to take pills to control the disease. The members also observed the time of taking medicines and warned them to take medicines in case they forgot as shown by the following statements:

- "... They always warn me not to forget to take medicines. If I forget to take medicines, when my younger brother come to see me, he will read the time for taking medicine and ask me whether I forget taking medicines." (Pen)
- "... My mother always warns me not to forget to take medicines, other members in the family always ask me if my medicines run out or I need to go to receive the medicines." (Leur)
- "... My parents know well about my medicines and always ask if I take them yet. I, myself, don't know much about the medicines but my mother would read through all the instructions and warn me everyday not to forget to take medicines." (Ked)

- "... When I go to the hospital to receive medicines, my husband would order me to take them until they run out. He would read the instructions and reiterate that I take medicines as indicated by the instructions." (Rut)
- "... My father and my wife would control me about taking medicines. If it's time to take my medicine, they would warn me or sometimes bring them to me and watch me taking medicines." (Roen)

With regarding health seeking, the informants told that after knowing they were HIV positive, all members in the families tried to seek the ways of treatment to heal the infection or illnesses in order to sustain them to live as long as possible. These ways of treatment composed of traditional treatment and conventional treatment.

The nine informants described that their family members tried to seek the traditional ways of treatment like using herbs or herbal medicine for them. Seven of the nine informants would tell the informants about the information on herbs or traditional treatment and also attempt to buy or find herbs for them. One informant was persuaded and taken to receive treatment by the method of meditation and another one informant told that he was recommended a place of treatment as shown by the following statements:

- "... My mother and aunt have sought medicines for me. They told me to take them. The medicines are both for eating and for melting in the water for cleaning me. They told that these medicines could encourage me eat more. I'm very happy that they've taken better care of me than before." (Bua)
- "... My father has sought herbal medicine called Fa thalai jone (Andrographis paniculata) and boil it for me to drink." (Lar)
- "... If my mother heard there're good herbal medicines, she would tell me and try to seek them for me. Now I'm taking Mara kee nok

(Momordica charantia Linn). When she went to the hospital to take some medicine for me, somebody told her about it so she tried to seek and bought it for me." (Leur)

- "... My mother would buy medicines that are rumored very good. She's bought a lot of medicines especially herbs and boil them for me to drink." (Tim)
- "... When I have cramps and fever, my mother would bring herbs like Rak dok ban mai roo roei (Globe amaranth roots) to boil with rice. It tastes very bitter, but drinking just once makes me recover quickly." (Ked)
- "... My father is concerned about me. If he hears where there're good medicines and herbs, he would immediately tell me. Sometimes he goes there to buy those medicines like herbs for me." (Noy)
- "... He mixes Thai herb Fa thalai jone (Andrographis paniculata) with honey and makes them up as tiny pills. He would give me 2 pills to eat before sleep and he himself takes 3 pills. I must take them in front of him, if not, I might be blamed. He also attempts to push me eat more herbs and bitter vegetables like Phak kee lek (Cassia Siamea Britt) and bitter gourd. I never liked these vegetables until he cook food containing these vegetables. I think it's o.k. but I don't like it much, just try to eat some." (Rut)
- "... Someone told that Luang Poh (an old monk) came to a temple to help people, so my parents took me to see him and stay at the temple and do meditate... I have a massaging oil to cure my numb legs. It's a yellow liquid medicine I got from Luang Poh. I applied it to massage from my knees to my ankles. My father massaged them, sometimes my wife did. I couldn't massage myself because my hands were also numb. They massaged everyday." (Roen)
- "... My mother watched a T.V. program showing that there's a place which is well-known for treating people with AIDS in Lop Buri, so she urged me to go there." (Ek)

According to the conventional treatment, seven informants told that their family members reminded the informants to receive a medical examination including going to get medicine for them, and taking them to see the doctor at the hospital or clinic as shown by the following interviews:

- "... If I had some little symptoms, they would tell me to see a doctor." (Karn)
- "... My mother took care of me when I was sick. She told me to see a doctor. If I didn't want to see the doctor, she might be worried so she brought me medicines or told my elder sister to buy medicines for me... When I'm sick, my nephew would take me to the hospital." (Lar)
- "... When I was sick for several days, my mom took care of me and forced me to see a doctor. She told it wouldn't cost much money."

  (Tim)
- "... When I'm sick and have to go to the hospital, my younger brother who takes me to the hospital by motorcycle." (Pen)
- "... I would see if I can go to see a doctor by myself when I fall ill, but if I'm in no condition to go to see him by myself in case I bleed or have lower blood pressure, that I can't move and help myself, so I have to depend on my mother and my elder brother or other people to send me to the hospital." (Ek)
- "... If I have a fever, several of them would pay me a visit at the hospital. Or if I go to the hospital to take an injection to my eyes to cure my vision loss, they would take turns to take me to the hospital, they're willing to do this." (Leur)
- "... If I'm sick, my elder brother would take me to the hospital.... In case that I'm getting worse at night, my wife would phone my elder brother to take me to see the doctor and then he would drive from his house in San Kam Phaeng District to take me to the hospital." (Dui)

#### Supporting for Dependent Care

The informants told that supporting for dependent care was the caregiving they received from their family members, and they also need of supporting for dependent care from their family members including receiving and needs of financial support, and caregiving for illnesses or disabilities.

With regarding the financial support, eleven informants perceived that they need and received financial support from the family members. The financial support consist of household expenses, personal expenses, expense for their children and for treatment costs as shown in the following interviews

- "... I can't work so I don't have any earnings. My wife is the only earner so she pays all household expenses." (Kam)
- "... All household expenses are paid by my father and mother." (Bua)
- "... He's given me all his earning but never asks me what I've spent for. He knows our spending is higher but our earning is still the same. So he told we should be economical... ... If I lack money, I can borrow it from my family and will give it back when I have. My mother and mother in law also lent me some money to buy this motorcycle." (Rut)
- "... My brothers and sisters gives me a financial support but they don't give money to me directly. They would give it to my mother and I could borrow some from her. Mostly, my elder sister has given rice and money to my mother and sometimes buys food for me. If my mother has any money left over, she would buy pants or a shirt for me. (Ek)
- "... If I'm broke, I can borrow money from my father or mother but if I have, I'll give them some. It's like helping each other." (Karn)
- "... When I tell them that I don't have money, my elder sister and sisterin-law would give me some, fifty or twenty baht.... Sometimes I didn't tell them but they ask whether I have money, if I don't, they would give me twenty or thirty... Sometimes my younger brother gave me one hundred or fifty." (Pen)
- "... I could borrow money from my elder sister. Most contribution is from my elder sister.... When I'm sick and must stay at the hospital, they would pay for all treatment costs." (Lar)
- "... I would bother my elder brother with my expense if I'm really in need... Sometimes he asks me whether I have any money. If I don't have no any money, I'll tell him then he'll give me some money... He also rents this house for me and pays for all household expenses." (Dui)

- "... My father and mother support me for my family's expenses. And my mother gives 15 baht everyday to my child for spending at school." (Ked)
- "... My mother has given a financial assistance to my family. She also pays for my child's tuition fees and other expenses." (Tim)
- "... My brothers help me because I don't have any earnings. They join to pay for my expenses of drugs and medical treatment. Sometimes they pay for half the expenses but sometimes they pay for all." (Leur)

Caregiving for illness. The informants described that when they were ill due to HIV-infection, not only they received care from their families but they also need care from their families.

With regarding receiving caregiving for illness at home, the informants told about the care provided by their families. Eight informants stated that their family members provided care including hygiene care, eliminational care, nutritional care, care for taking medicine, Using herbs for relieving the symptoms, and wound care as follow:

- "... If I'm ill and stay home alone, sometimes my younger sister but mostly my mother would carry a bucket of water for me and then I'll clean myself. After that, my mother would clean everything up and empty the chamber pot for me. Sometimes my younger sister empties it for me."

  (Ek)
- "... When I was seriously ill and unable to help myself, my mother helped supporting me to go to the bathroom. I didn't want her to help me but my mom said she would do for me. She washed my hair and then I took a bath myself." (Tim)
- "... I have a fighting spirit but my health is weak. But my wife, she give me the best care as well as wife can do for her husband. She bathes me and does everything for me as I can't move and help myself. She's with me all the time to help me." (Dui)

- "... If I'm ill, my mother would seek for some food that I can eat for me."
  (Lar)
- "... If I'm unable to move, I would ask my mother to pick the medicines for me and she would bring them to my bedroom upstairs because I'm unable to walk. Sometimes I forget to take medicines, but she doesn't, so she would bring them to me. She would ask me which medicines I need so that she can arrange them in a small box and then put it in my bedroom upstairs. She also prepares paracetamol separately so that I can take them before meal and after that she would bring food to me." (Ked)
- "... I had abscesses on my back and legs and needed them cleaned and bandaged. Sometimes my brother who works at Sripat came to bandage my wounds. He did very neatly." (Leur)
- "... I had a big wound on my left groin because of the burst abscess. My father took me to the hospital to have my wound cured. Then he took me to the temple and my parents stayed with me there and also cleaned my wound. When I returned home, my wife cleaned and bandaged my wound." (Roen)
- "... When I can't do anything, she will help me... I had a big abscess, my wife took me to see a doctor. He prescribed me some medicines. After that I told my wife to clean and bandage the wound until it was relieved... also when my arms itched, my wife bought me a medicine." (Kam)

With regarding caregiving for illness at home, six informants indicated that they need and received care from their family members involving nutritional care, close caring, encouragement, and hygiene care as shown by following interviews:

<sup>&</sup>quot;... I want them to take care of my food when I'm seriously ill. If I'm unconscious and can't eat, I want them to cook boiled rice for me. I don't know if they can do because they don't know much about the food that is suitable for patients. They're unlike today's people who know well about food." (Ked)

<sup>&</sup>quot;... when I'm so seriously ill that I'm unable to move and eat much, I want them to cook mild food for me like boiled rice." (Leur)

- "... I need my beloved to be beside me and ask me what I like to eat. That would make me feel very happy. People with HIV/AIDS want to eat everything they like as it's near the end of life but they can't eat much and that might discourage the visitors. For me, I can't eat with them at the table, so they would bring me a tray carrying food and rice." (Karn)
- "... She helps me when I can't move or help myself. If I'm seriously ill, she would feed me and sit beside to take close care of me. If I want something, she would find it for me." (Kam)
- "... If the water jar is empty, they will fill the water for me.... My wife knows all what I need. When I want to take a bath, she would bring me my clothes and then take me to the bathroom.... My wife brings me a chamber pot when I want to pee and then she empty it. I need a chamber pot when I pee or shit and somebody must bring it for me." (Roen)
- "... After I use the toilet, my elder sister would clean up for me because I can't help myself." (Pen)

Seven informants told that sometimes they have symptoms of illnesses and have to receive treatment at the hospital. Two of these informants indicated that their family members helped them deal with the contact and coordination with the hospital when they were ill and had to receive treatment at the hospital, while five informants told that their family caregivers went to hospital to watch over or visit them. The informants who live with their wives told that their wives would watch over them at the hospital while those who were single indicated that their mothers would take that role whereas other relatives like brother, sisters and fathers would visit them rather than watch at their bedside as showed in the following interviews:

<sup>&</sup>quot;... My elder sister coordinated with the hospital and contacted with the doctor to cure me." (Leur)

<sup>&</sup>quot;... When I have to receive treatment at the hospital, my elder brother would deal with room, medical fees, contacting with doctors and nurses

and everything. He would drive to send me to the hospital. Sometimes he drove from San Kampaeng in order to take me to the hospital and then get everything done." (Dui)

- "... My wife watched over me at the bedside at the hospital so that if anything wrong happened to me, she could call the doctor immediately. My younger brothers/sisters also visited me and brought me some food. Sometimes my mother cooked food for me and came to visit me at the hospital." (Kam)
- "... My wife watched over me all the time and stayed with me in the special room. She took care of me by buying things for me. She bought me something to eat and fed me as I was very weak at that time." (Dui)
- "... When I received treatment at the hospital, my parents and my wife took turns to watch over me all the time. Other relatives brought me some food and my parents or my wife would feed food, water and medicines to me or sometimes rub my body." (Roen)
- "... when I stayed at the hospital. Mostly, my mother visited me while other members in the family bought something for me. Every time my mother visited me, she brought boiled rice for me. Sometimes she emptied my chamber pot or rubbed my body. Once I stayed at Suan Dok Hospital, I couldn't eat food provided by the hospital, so my mother brought me cooked rice, water, milk and newly baked bread. Although I couldn't eat them all, I tried to eat some and when I felt better, my mother still fed me." (Ek)
- "... When I stayed at the hospital, my mother took care of me when I had my bowel movement as I didn't want a nurse to do that for me. So my mother did it for me. She would take a chamber pot for me when I want to have my bowels removed. After that, she would rub my body and clean everything up for me, even my bottom." (Tim)

## Supporting for Social Care

Five informants stated that they received family support for social care. One female informant told that after she knew she was HIV-infected, she felt shame and dared not to meet other people. However, the family members encouraged her to join the activities held by other people in the village so that she could seek help from each

other in the future. Another one female informant told that her family suggested that she take part in the activities that only held by their relative because they were afraid that she might be disgust by other people in the district. In addition, another three informants told that the family members also encouraged the informants to contact with groups or organizations related to people living with HIV/AIDS as shown by the following statements:

- "... I don't have courage to meet other people and I feel shame. I don't want to join any activities as I dare not to meet other people, but my elder brother and mother tell me to get involved in those activities. They said I should go as other people could help us in the future." (Pin)
- "... My family doesn't want me to join the activities held by people in the village because they're afraid that those people might dislike me. But if the activities are held by our relatives, they allow me to join." (Karn)
- "... I haven't been a member of the group yet when I stayed at my husband's house. But after I moved back to stay with my family, my mother took me to that house... (the HIV/AIDS group's name) and I has joined the group since then." (Rut)
- "... Now I don't have friends. After I'm infected, I don't have courage to meet other people and make new friends. I'm not sure if they hate me or not and I don't want people to know that I'm infected. So I only make contact with other infected people at the center (New Life Center, ChiangMai). My mother introduced me to the center. At first, she went to the public health service to buy the medicines for me. There she met a volunteer named ....who gave good advice to my mother. Then my mother took me to the center." (Ek)
- "... My relative took me to join the AIDS people society. She told me not to be shy because she's also infected." (Bua)

#### **Preparing for Dying**

The informants told that they want their family members to prepare for thier dying. They need the family members to look after their children or father/mother

after they die of the disease. Five informants stated that they need their families to look after their children, meanwhile two informants who had no children told that they need their families to look after their parents as shown by the following statements:

- "... If I die, I'm concerned who will take care of my child. He must be an orphan. He might live with my elder sister but I'm not sure how much my sister would love my child... I told them to sell my house and property after I die and then give the proceeds to my child..." (Pen)
- "... If I'm terribly ill, I want my mother to take care of my child until the graduation." (Ked)
- "... I want my child to be treated well. Now my mother takes care of everything for my child, she pays for tuition fees and other expenses. I want them to give more love to my child." (Tim)
- "... After I die, I want them to be a shelter for my child. I want them to take care of my child even he is rich or poor, not desert my child. I'll still have a concern and worry about my child after I die. I want my child to live in the society happily without being blamed or criticized by other people." (Noy)
- "... I want them to look after my child. I'm afraid that nobody will take care of my child after I die. But my younger sister in Bangkok told me that she would nurture my child after I die. She's over 30 years old and still unmarried." (Pin)
- "... I told my wife to stay with my parents and take care of them. I don't allow her to move back to live with her parents after I die. I don't know if she will obey me or not." (Roen)
- "... I need my brother to graduate so he can be dependable for my father and mother in the future because I can't be dependable for them anymore." (Karn)

Two informants told their family members in advance about the funeral after their death. They told them how to deal with their funeral rites and ashes as follow:

- "... I told them to take my dead body to hold a funeral rite in Chiang Rai and I want my body to be cremated. After that, keep my ashes there. I already told them." (Dui)
- "... I want my dead body to be cremated and my ashes to be brought to Lampoon and be kept there. I told them when I paid homage to my grandmother's ashes in Lampoon." (Ek)

### **Summary**

In conclusion, people living with HIV/AIDS perceived that receiving family care would prolong their lives. The family care is essential for them to stay alive and to sustain their lives. It is of critical importance because it is absolutely necessary for their life. It is also a strong will for fighting. The elements to support for survival include caregiving for promoting and protecting health, supporting for dependent care, supporting for social care, and preparing for dying.

#### Discussion

The results of the study "the experiences of receiving family caregiving as perceived by people living with HIV/AIDS" found 3 themes that reflect the phenomenon of family caregiving including caring, care received from family members, and lenghtening life as described follow:

#### Caring

"Caring" gives a meaning of providing care in the forms of helping and supporting mentally. It puts an emphasis on the emotions and feelings stemming from receiving family care. Being diagnosed as having AIDS would bring mental losses including loss of control, loss of independence, loss of personal capability and loss of self-confidence. The patients would fear, get stressed, worried, discouraged and depressed (Green & McCreaner, 1996). In addition, when the symptoms of disease appear more, the patients would have skin symptoms, skinniness and be so tired that they can work anymore which might have more impact on the patients' mind. Therefore, the informants think that family care should be given with a sense of "caring" comprising of will power and psychological support. This study result is consistent with the study by Maneerojjana (2001) about the meanings of the care of people living with HIV/AIDS from the caregivers' point of view which showed that caregivers play a role of offering caring and concern. They also do not desert, but give will power and psychological support to people living with HIV/AIDS to make them a

stronger mind. Furthermore, care with a sense of caring would make patients have hope, trust, certainty, emotional security and well-being (William et al., 1997).

Caring is will power. From their experiences of receiving family caregiving. the informants stated that caring is the will power that they received from their family. The word "will power" comprises of two words "will" and "power". The word "will" means what functions to know, feel and think whereas the word "power" means energy or what creates a power and strength. Therefore, the word "will power" means the encouragement to create confidence and strength mentally and sentimentally (the Royal Institute Dictionary, 1982). In this study, the issue most mentioned by the informants on the care given by the family members is to receive will power originating from getting love, concern, sympathy and unprejudiced from family members. Moreover, the concept of 'caring' has a correlation with the concept of 'love'. That is the word 'cherish' which means love is derived from the Latin word 'carus' which has the same meaning as the English words 'care' and 'caring' which also mean love (Eriksson, 1994). For love and being a family, there is a saying that a family that has a love-based living is a happy family. Love is the most important thing in the family as it creates the feeling of concerns about health, making members in the family try to find time for each other, understand the feelings and helping each other without selfishness (Chutikul, 1994). Family is the closest and most important source of social support and also the source of sincerely giving love and warmth to members in the family (Thongkamrod, 1998). It also found that love given by caregivers to HIV/AIDS patients is a reason why caregivers take care of HIV/AIDS patients (Maneerojjana, 2001). This study finding is consistent with the study by Sangchart

(1997) which stated that people living with HIV/AIDS often choose to seek the support of will power from their family members. As they are the closest to people with HIV/AIDS, combined with the love between people in the same family, they would find the right ways to give will power to people living with HIV/AIDS by using words and treatment that show love, caring and not deserting them. It is also consistent with the study by Peri (1995) about the nursing activities encouraging the spirit of HIV/AIDS patients which found that HIV/AIDS patients realize they are still loved and concerned by their families, encouraging the patients to have more will power.

In addition, the results of this study also found that the informants received "sympathy" from their family members. Kermode (1995) explained that when members in the family know about the infection state of HIV/AIDS patients, the most important thing to sustain the patients is to assure them that they will stay alive without any symptoms of illnesses and will not die in the near future, including forgiving, not aggravating them and giving consultation. In addition, the family is a mental shelter for members in the family when encountering problems (Limanonda, 1998). In the study by Thampanichawat (1999) about the experiences of HIV infected mothers in rural areas, it found that people whom HIV/AIDS patients need to seek consultation or assistance mostly have blood relation with the patients such as mother, younger sister and elder brother, etc. It is considered a way that the informants used to adjust their minds and emotions for dealing with problems; simultaneously, to strengthen the informants' minds to have will power. (Sangchart, 1997) The explanations about the meaning of care mostly show that care originates from love,

concern and sympathy. It is the feeling that excludes the feeling of dislike of the caregivers (Morse et al., 1990; Maneerojjana, 2001). Especially, those who act as caregivers are mothers. When a mother has to take the roles of taking care of her children who are infected with AIDS, she would look after her children with love and attention and she can overcome the fears over possible dangers or damages (Reynold & Alonzo, 1998; Songwathana, 1998)

Psychological support was the needs of family caregiving as perceived by PLWAs. It is generally known that the HIV-infection and the AIDS-related illnesses are incurable. As a result, the psychological support is considered the best way of treatment to cure HIV/AIDS patients today and is given to HIV/AIDS patients who have suffering, depression and despair (Greif & Golden, 1994). The psychological need is delicate, complex, profound, intangible and inarticulate but it can be expressed and realized. Furthermore, the psychological need can be regarded as the highest degree of demand that other people are supposed to do to satisfy PLWAs (Kompayak et al., 1998). Caregivers can meet the patients' need by giving will power, consolation or even mild touch in order to comfort the patients that reflect the warmth and acceptance (Thaniwattananon, 1995). Moreover, if desperate HIV/AIDS patients are mentally supported, they will not feel lonely (Peri, 1995) This study finding is consistent with the study by Songwathana (1998) about the culture of self-care among persons with HIV infection and AIDS in the Southern of Thailand showed that the best care from family is the psychological support and the study by Thampanichawat (1999) about the experiences of Thai women infected of AIDS found that people close to them show their acceptance, support and assistance of people living with HIV/AIDS by offering the mental, emotional and social support, giving understanding, forgiving and paying more attention.

The informants also stated that they need their families to understand their emotions and feelings as indicated by Kompayak et al. (1998) that HIV/AIDS patients always need understanding. Moreover, the informants stated that in the first stage of knowing the HIV infection, the family members and them do not know how to treat to each other. This result is consistent with those of Sangchart (1997) and Poorisit (2002) which found that some infected people indicated that they did not have confidence, faith and trust but doubt about the ways of transmission of the disease that could be spread by other means for example touching, being closeness, or sharing instruments. In this study, the informants also need their families to understand about AIDS and treatment between members in the families. As the informants must depend on other members in the families to take care of them when falling ill; therefore, if the members have the right understanding about the illnesses of AIDS patients, that would make the HIV/AIDS patients get right and proper care and help as shown in the saying that families that could support, help and take care of AIDS patients very well must have those who have the right knowledge and understanding (Chandee, 1999). This result is consistent with that of Kusuma Na Ayuthaya & Somarin (1998) which found that the infected people need an advice on health care and an assurance that their family members could help them in case of the appearance of illnesses. It is also consistent with the study by Thipthong (1999) which found that when HIV-infected people have any symptoms or signs of illnesses, some members still lack knowledge and skills of properly taking care of the patients. However, Brown & Powell-Cope (2002) found that caregivers would not initially understand much about the role of taking care of the patients, but the experiences gained later would allow them to have more understanding.

Moreover, the informants described that they need psychological support by being treated as normal people, not be viewed as infected or a carrier that would be disgust, separated or discriminated. Also the study by McCann (1997) indicated that responses from informants who have experience with patients who have HIV infection suggest that there is a need to be non-judgemental and accepting of marginalized individuals, both on a personal and professional level. Most infected people always expect to have a normal life and think that they are still healthy and able to work. That point of view would build confidence to the infected people in order to have a will power and hope in their lives (Srinoi, 2001). If the family members see that the informants should play a role of HIV/AIDS patients who need to be treated differently, that might make the informants lose their self-confidence and self-esteem. The heart of making the infected people feel that they are normally treated is to treat them as a normal person, not an infected person who is disgust, and not a patient who must depend on others and need special care and support. Caregiving in this way would allow the infected people to feel happy, valued and not discriminated and be able to have a normal life (Rabkin, Remien, & Wilson, 1994; Kermode, 1995; McCann, 1997; Meredith et al., 1997). The result is consistent with the study by Maneerojjana (2001) which found that doing "as usual" and "doing as before" demonstrate to the patients that they are not patients but like other normal people. Participating in the family's activities is a good method that would let them forget for a while that they are infected and might make them feel happy and accepted to live together normally. That is HIV/AIDS patients want to be accepted by their family members with the retention of relationship of the family and the desire to spend lives in the same way before they are infected (Sangchart, 1997; Srinoi, 2001).

In this study, the informants described that they need to be closely cared and touched by family members. They also want their members to pay a close visit at their bedside when they receive care at the hospital or cannot help themselves. Close care and touch do not only show that they are not disliked by their family members but also convey the feeling of warmth to the informants. It could be said that attention and caring could be expressed through acts of touching like holding hands and massaging body softly and willingly. These acts would show the warmth and acceptance (Thaniwattananon, 1995) that would make people living with HIV/AIDS feel that they will not be left alone (Peri, 1995).

## Care Received from Family Members

Care received from family members revealed the types of care provided by family members. In Thai society, members in the family would be assigned to act as caregivers as part of their duties and responsibilities as expected by the society under the old Thai tradition (Pookboonmee, 1998). That is when somebody in the family becomes sick, he or she expects other members in the family like children and relatives to take care of him/her. Meanwhile, most people see that family members are helpful for the members who are ill and it is their responsibility to take care of those sick members (Linsk & Poindexter, 2000). This result is consistent with that of Wood

(1991) who studied the meaning of caregiving from the experiences of caregivers, who were providing care to an individual who recently had been discharged from a physical rehabilitation program, found that these caregivers believed that the caregiving was their responsibility by virtue of relationship, or that no one else was available to assume the caregiving role.

In this study, the family care as perceived by the informants can be classified into self-devotion for care or care due to duty.

The family members' self-devotion care originates from the family bond as the Thai family has the strong relationship in accordance with the social norms. The family is tied by the bond and a sense of caring between father, mother, and children; husband and wife; and other relatives in the same family. Thus, that leads the family to accept, support and assist PLWAs to live with other members in the family normally. As a result, that would stir people's desire to take care of other family members who are ill or unable to help themselves (Linsk & Poindexter, 2000). For example, the bond between mother and child and the bond between husband and wife would make the family members to act as caregivers with the feelings of love, attention and sacrifice (Reynold & Alonzo, 1998; Songwathana, 1997). The caregivers would change their way of life to provide care. These findings are in accord with the past literature review such as Musolf (1991) found that changes in lifestyle have to be made to meet the increasing demands of caretaking of elderly, ill, or disables people. Furthermore, several studies about taking care of PLWA from the caregivers' point of view found that caregivers have to change their way of life to take care of PLWA (Chancharas et al., 1994; Chunhapran et al., 1999; Tolliver, 2001; Maneerojjana,

2001). The study by Im-em & Phuongsaichai (2001) on the similar issue found that 70 % of those who take care of AIDS patients have to take days off in order to look after the patients. For the findings in this study, it found that those who sacrifice themselves in order to take care of PLWAs with willingness are mother and wife which is accord with the phenomenological study by Wood et al. (1991) on the caregivers' experiences of taking care of PLWAs, showing that the majority of caregivers are women who take care of PLWAs because of the bond which makes them devote all their energies to look after the patients. It can be explained that due to the cultural values that has been implanted in Thai society, women especially mother and wife would be willing to take over the roles of caregivers as expected by the society as it is deemed their responsibilities (Rhucharoenponpanich, 1999) as well as their love, bond and sympathy. Particularly, a mother in Thai society would have more attachment with her children than other members in the family. Most mothers would be willing to sacrifice themselves for their children without conditions (Samienpetch, 1998). In addition, Thai society would see the mother as the one who can sacrifices her own happiness for her children and who loves her children more than themselves. That is the pure love which makes her ready to do everything for her children with all her heart (Santasombat, 1992). It could be explained that the understanding, sympathy and compassion towards PLWAs would motivate the mother to look after her children who are infected with the disease (Sirapo-ngam, 1996).

The findings showed that the informants also perceive that their family members do not want properties or money in return for the care they give to them.

Besides the happiness resulting from providing care, it could be explained that when

family members look after other members who are ill, they would feel that they are worthy, capable and needed and they would also be appreciated by others as indicated by Lim et al. (1996) that having sick members under their care would make the caregivers feel good and have satisfaction from helping and taking care of them. According to the Buddhism, พระเทพเวที [Phra Thepvethee] (Prayuth Payootto, 1993) stated that the feeling of giving comes from love and good desire towards people whom one has a sense of attachment. That love and good desire would make one happy with giving. When others are in trouble, love would become a sense of pity and desire to help them out of the trouble and it would bring an attention to those in trouble. It is a feeling of sacrifice in one's heart which he or she wants to help others who are ill even though that might cause him or her problems and he or she do not get anything back in return. It is consistent with the study by Maneerojjana (2001) on the caregivers' experiences of taking care of PLWA which showed that caregivers indicated that they felt happy to take care of their family members who are infected with AIDS. Meanwhile, Suwanno (1998) suggested that most caregivers are relatives or members in the family who take care of the infected people by focusing on giving care and assisting without any returns of wages or rewards, and Sirapo-ngam (1996) indicated that family members who are sympathetic, pitiful and concerned about the patients always feel happy to take care of the patients. That is in accord with the findings of Loorsakul (2001) study which found that parents or spouses of AIDS patients would be willing to take care of the patients and also get satisfaction from looking after them because of the love and bond in the family. However, two

informants in this study indicated that although they are looked after by their wives with willingness and sacrifice, they sometimes feel that their wives would express their stress by complaining or showing the feeling of bother when taking care of the informants. Given the data collected from the interviews, it found that the wives of those two informants manage almost everything in the family from taking care of the informants, doing housework and working to support their families. Also, those two informants have the symptoms of illnesses for the periods of 4 and 7 years, respectively. According to Gaynor (1990) and Monahan & Hooker (1997), those who have taken care of the patients for a long time would feel tired and stressed, while Lim et al. (1996) suggested that family members who have their permanent jobs would have to take more burdens from taking care of members who are ill; thus, resulting in high tension. If the patients are weak due to the AIDS-related illnesses and have to depend much on others, then caregivers could feel 2-3 times sad and stressed than general people (Mcshame, Bumbalo, & Patsdaughter, 1994). The result is consistent with the study by Hughes, Giobbie-Hurdur, Weaver, & Henderson (1999) which stated that caregivers who are married normally live in the same house with the spouses who are sick and they have to take care of the patients all day long. If those who act as caregivers are wives, they have to play other roles at the same time such as taking over the role of family leader instead of their husbands who are ill, finding income to support the family and doing housework. These burdens would push the wives who act as caregivers under high stress. The study by DesRosier et al. (1992) on the experiences of wives in taking care of their husbands who suffer from multiple sclerosis found that the wives spend almost throughout the day doing housework and

looking after their husbands, resulting in the feelings of anger and frustration. In addition, one informant in this study indicated that although his mother takes care of him with love and willingness, she is still afraid of being infected with the HIV. Therefore, his mother adopts the method of separation by not having a meal together, separating spoons and dishes, not using the same bathroom and preventing the informant from contacting his younger sister. The informant also told that after knowing he is HIV positive, he and his family members including his mother are uncertain about how to treat with each other. It could be explained that there are still some misunderstanding about the disease and that would make the AIDS-infected people be separated and disliked even by those who have the closest relationship with the infected people. It could be said that an obstacle that prevents the care of PLWHA is the fear over the infection. Even the value of love and sympathy could not overcome that fear (Songwathana, 1998).

In addition, this study found that receiving care from parents would make the informants feel that they cause their parents troubles. According to the findings, the informants' parents are in the old age which are supposed to stop doing hard works whereas the informants are in the working age who are supposed to take the responsibility of taking care of the family and relieving the parent's burdens; ironically, the parents must take the burden of looking after the informants who are often ill due to the disease and have to give psychological support to the informants who suffer from HIV. Furthermore, in the culture of Thai society, children are expected to take care of their parents as a way to show their gratefulness. Especially, all informants in this study are Buddhist so the Buddhism teachings must be followed

by all Buddhists. That is the Buddhism have such teachings that "Children have the responsibility to take care of their parents for the bringing-up" and "The gratefulness is really the morals of good people." as indicated by พระเทพเวที [Phra Thepvethee] (Prayuth Payootto, 1993) that children in Thai society have five roles to perform for their parents. These roles are taking care of parents, helping do housework, maintaining the family, behaving appropriately and making merits for parents after death. It also stressed that in the Thai way of life, there is nothing greater than parents. However, the result of this study showed that the informants cannot perform those expected duties; instead, the parents in the old age must take care of their children in the working age who are suffering from the illnesses physically, mentally and socially. Especially, if the parents look after the informants with the self-devotion care and willingness, that would even make the informants feel that they cause troubles to their parents.

In this study, the informants told that their elder and younger brothers and relatives are forced to look after them due to the duty as they does not have anyone else to take care of them but their family. Therefore, the care given by these people is distant and the feeling of dislike is expressed; especially, when the informants has visible symptoms of illnesses such as skin rashes, cough and tuberculosis which are often found in PLWA (Kongsuriyanavin, 1997; Poorisat, 2002). It could be explained that Thai society is comprised of a majority of Buddhists and พุทธทาสภิกษุ (Buddhadasa Bhikku) stated about the Buddhism teachings in his book "Handbook For Mankind" that a duty is important that one has to perform correctly and he should

not let any faults happen. Taking care of those who become ill is regarded the family duty. Therefore, an ignorance or negligence of that duty could be reproached by the society (Sirapo-ngam, 1996). When the informants need help and care, their family members cannot deny their request as they are afraid of being criticized by the society or neighbors if failing to perform that duty. If the duty is performed with the feelings of love, attachment, pity and concern, the care given to the patients would be done with sacrifice and willingness, but if the care is given distantly with the feeling of dislike, that would make the informants perceive that they are treated because it is just the family members' duty.

# Lengthening Life

The family care could prolong the informants' life. It means that the family care is essential for the life of those afflicted with HIV and AIDS. Care is essential for life (Morse et al., 1991). That society is founded from family which is a basic institute for one's living (Chutikul, 1994). These remarks could be explained from the experiences of PLWAs in this study which the informants perceived that the family support is essential for them to keep alive. Because of the infection of HIV and AIDS, they have to depend on family members whom they consider necessary. Without family care, the informants might have more symptoms of illnesses and die rapidly. Moreover, family care would energize them to have power in fighting the problems and not feeling depressed as stated by Phongphit (1993) about the conditions of HIV and AIDS patients in Thailand as follows:

"Most AIDS patients die in a very short time as they lack love, understanding, sympathy, care and attention. But some are still alive until they turn 50 years old and have normal life as others. This group of people is trying to tell that most AIDS people didn't die of AIDS but of lack of love and social contact. They're separated by the society and severed from the human being. How could they be alive? Many AIDS-infected people found that when they get will power, love and assistance from others, their immune system which had been decreased suddenly increases as much as other normal people. Today they announce that they are cured even though AIDS is still in their body but it's like other diseases that exist in our body but we're still alive."

The informants realized that family care is the thing that cures and keeps them alive. Family members would play important roles in giving warmth, attention, care, consult and will power for the informants to fight AIDS (Sangchart, 1997). Family care would change the informants' feelings of depression into hope that would activate the immune system of PLWAs; thus, that would enable the body to improve the fight against the disease. The development of disease to critical stages would be slower (Gaskins & Brown, 1992). Apart from being the society's main institute which gives support both physically and financially in many aspects such as food, health, rest and treatment, family is the mental and emotional support source which encourage the patients to have will power, strengthen them to fight with the obstacles and revive their hope (Health Education Division, 1998). That is a way to treat both mentally and physically simultaneously (Chanta, 2001). The will power from family is also a part that helps urge PLWAs to take care of themselves for their beloved (Maneerojjana, 2001), for having a normal life in the society and for achieving their ultimate goal of prolonging their life (Sangchart, 1997).

Supporting for survival is the care from family members with an aim to prolong the patients' life. They would take care of the patients even when the patients

are still able to help themselves or even when they are so sick that they cannot help themselves and the family would look after until the patients die. For example, the family would provide care for health promotion, give a support when the patients need, offer social care and prepare for the death of the patients. This result is similar to the finding of Songwathana (1998) study that the caregivers' activities are consist of obtaining medical care and treatment for the patient, buying medicine or supplementary materials, providing personal care, providing special care and treatment such as dressing wounds and skin massage, and arranging for an appropriate religious healing ceremony or rite.

The informants told that the family care is aimed at promoting the health. Therefore, the activities from family are focused on promoting and maintaining the strong health as well as having appropriate activities and rest (Brennan & Moore, 1994). The findings are consistent with the study by Srinoi (2001) about HIV-infected people in the northern part of Thailand which stated that most of the infected people adopt the methods of promoting and maintaining their health by focusing on paying attention to food, drinking water, the body's cleanness, avoiding things that might undermine their health, stopping eating harmful food and having enough rest. Meanwhile, the study by Im-em & Phuongsaichai (2001) suggested that having sufficient nutritious food together with having supplementary diet or herbal medicine and having enough rest as well as avoiding doing too much hard works would promote PLWAs to have strong health. Moreover, the studies by Songwathana (1998) and Im-em & Phuongsaichai (2001) showed the consistent findings that health care is important to prevent PLWAs' illnesses from collapsing and is the best alternative for

family members to do for PLWAs on expectations that having strong health could prolong the patients' life.

In addition, the health promotion care is aimed at PLWAs to have as strongest health as possible and control the appearance of illnesses as little as possible. As it is generally known that AIDS is incurable, the existing methods of treatment only remedy and delay the illnesses occasionally and they cannot treat the patients to be completely cured from AIDS. Then, the way of treatment by using herbs is an alternative for the informants and their families to control and delay the HIV-related symptoms (Chanta, 2001) which is a way to reduce the serious illnesses of the disease and that could prolong the informants' life. Seeking various ways of treatment is another method that brings hope to PLWAs (Langkarpint & Warrier, 2001) as shown in the study by Im-em and Phuongsatchai (1999) about the household resources allocation and response towards AIDS-related illnesses among people in 4 villages in Chiang Mai Province. The study found that after knowing the HIV infection, most AIDS patients would seek ways of treatment although they know that AIDS is incurable. However, they still have hope that these treatment can prolong their life and help them have strong health which might slow the symptoms and lengthen their life without the appearance of illnesses. The study is in accord with the study of Songwathana (1998) about PLWAs in the southern part of Thailand and the study of Poorisit (2002) about PLWAs in the northern part of Thailand. These two studies found that the ways of treatment of PLWAs include the traditional and conventional medicine treatments, comprising of preparing or buying medicine or supplementary diet from hospitals, pharmacies or other sources, using herbs, meditating and taking care of their health, all of which is considered another alternative being used with the conventional medicine.

When the informants need to depend on family care, they would get a financial assistance from their family members for the cost of living, children's expenses and medical fees. These findings found that all informants are in the working age, some do not have earnings whereas those who have work get a small amount of earnings. Among the total 14 informants in this study, 8 are HIV-infected people and the other 6 are AIDS patients. Due to the fact that these informants would have the symptoms of illnesses occasionally and they are unhealthy, there are little chances for them to find jobs. Meanwhile, they have to spend money to treat and control the illnesses. The more often they fall ill, the higher medical costs they have to pay. However, the need of living requires the informants to spend money for household and children; therefore, that drives them to depend on the financial assistance from the family as stated by Tumonsoontom (1998) that most AIDS patients need financial assistances such as social security benefits, children's tuition fee, allowance and etc. The sources of funds for treatment are their savings and financial aid given by their family members (Im-em & Phuongsaichai, 1999)

With regards to receiving care at home, there are some interesting points consistent with the findings about caring. That is the informants emphasized the need of care when being ill at home. The findings showed that when the informants mentioned about the care they receive, they would always describe about giving care physically and mentally in the form of giving will power which the informants stated that stems from love, concern, sympathy which is expressed by comforting, forgiving

and consulting. Meanwhile, the informants stressed that they still need to be closely looked after and do not want to be left alone. That is the physical care. However, giving love, concern and sympathy is still insufficient for PLWA.

When the informants have symptoms of illnesses or are unable to help themselves at home, family members would take care of some daily tasks and activities such as warning the informants to take medicine, preparing and buying medicine and herbs to treat the disease as well as looking after in order to alleviate the illnesses. In this study, all informants have periodic symptoms of illnesses such as fatigue, skinniness and exhaustion. They would suffer from the pains on several parts of their bodies and have to depend on others sometimes or when their symptoms are strong or they are unable to help themselves (Green & McCreaner, 1996; Kompayak et al., 1998; Sherman, 1999; Maneerojjana, 2001). These findings are also consistent with the research result of Chanta (2001) who studied on the local wisdom in the cultural dimension of taking care of PLWAs in the northern part of Thailand. The study found that those who are close to PLWAs such as parents, spouses, relatives and friends who are also infected are the most important for looking after the health of PLWHA. Family members would themselves take care of the patients at home. Most infected people need physical care about hygiene or assistance in doing some activities periodically or continuously from those who can stand by them (Beedham & Wilson-Barnett, 1995). Family members including spouses, children and parents would be considered the source of supporting and helping patients with chronic diseases and patients with life-threatening diseases (Baker, 1999). They are also a network which would give advice on behaving, solving the problems and introducing the methods of treatment (Chancharas et al., 1994) by getting involved in the situations of the patients ranging from the diagnosis of disease, arrangement and program of various methods of treatment for the patients.

PLWAs would have periodic symptoms of illnesses as the state of the disease develops. The illnesses will increase and appear more often and they would be worsen into critical stages occasionally (Im-em & Phuongsaichai, 2001; Brennan & Moore, 1994). Due to these illnesses, PLWAs must receive treatment at the hospital from time to time. According to this study, the informants told about receiving care from their family members when they have to receive treatment at the hospital that the members would watch over or pay a visit when the informants stay at the hospital. The members would also help proceed with the contact and coordination with doctors. It is consistent with the study by Brown & Powell-Cope (1991) which suggested that the family would take care of the patients by taking them to the hospital, handling with the hospital proceedings and seeking the ways of treatment. Providing care when the patients need to receive treatment at the hospital is the family support that AIDS patients get most apart from love, concern and will power given by the family (Kusuma Na Ayuthaya & Somnarin, 1998). The informants who live with their wives told that their wives would watch over them at the hospital while those who are single indicated that their mothers would take that role whereas other relatives like brother, sisters and fathers would visit them rather than watch at their bedside. Meanwhile, brothers would help coordinate and contact with the hospital officials. From these phenomena, it could be explained that based on the social beliefs and cultural values in Thai society, women would be brought up and implanted to handle with the housework and help other family members while men would take the responsibilities of dealing with the expenses, contacting and coordinating rather than offering direct care. The findings also highlight the roles of mother and wife who devote, dedicate and sacrifice for taking care of by watching over and giving care when their children or husbands are sick and stay at the hospital. These practices require much patience and sacrifice as the circumstances at the hospital are different from the homes which are familiar. These findings also underpin the study by Andrew and Boyle (1999) which stated that in family care, men would take the roles of supporting, seeking facilities for giving care, coordinating in communications as well as providing financial aid for medical fees while women would take the roles of taking care of daily tasks for the patients' content.

After knowing that they are HIV infected, family members still encourage the informants to join the groups of HIV and AIDS infected people. Joining the group of people in the same conditions is a way that enables PLWAs to confront the problems and to live normally and peacefully like others in the society. As most infected people would be separated from the society, the group of HIV and AIDS infected people could be a supportive group for emotional and mental sides and it would provide PLWHA with a chance to meet and exchange knowledge, experiences and advice with other sufferers; thus, it would lead to an acceptance and would also be a compensation or promotion of acceptance by the family.

This study found that the informants would like their family members to prepare the readiness for their death. They want the members to look after their beloved including children and parents after they die. They also need the preparation

of selling their house and other remaining properties and give the proceeds to their children. For AIDS infected people who are married and have children, the matter of taking care of children is one of the most important problems (Chancharas et al., 1994) which is consistent with the study by Thampanichawat (1999) that found that AIDS patients who have children hope their close people to take care of their children after they die. The patients also save money for their children's tuition fees and the study by Srinoi (2001) found that AIDS infected women who have children want the guarantee for their children's future by needing someone to take care of their children. It is in accord with the study by Nakcharoen (2001) on the preparation for the death of HIV infected people which found that most HIV infected people have prepared for their death by setting the future plan for their family members to take care of the education, caregiver, house and funds of their children as well as the preparation for the management of heritage and property. Moreover, the informants need their family members to hold the funeral rite for them and collect their ashes by specifying the place where they want them to keep the ashes and the place where they want their body to be buried. As the HIV infection is seen the life-threatening disease that is incurable, HIV infected people must die of the disease (Flaskerud & Tabora, 1998). All informants in this study live in Chiang Mai province where the outbreak of AIDS is quite serious due to a rapid increase in the number of HIV and AIDS infected patients. In addition, most informants have seen their spouses, friends or people in the same village die of the disease. Getting the direct experiences from the death of people around them, seeing and getting involved with the stages before death of these people would create the awareness of death. Moreover, having attended the training courses or conferences about AIDS together with getting information from the publication of AIDS would make the informants realize that they would be sick and die in a short time as the informants always said when meeting with the researcher that "I don't know whether I'll meet you (the researcher) again. I don't know when people like us will die, may be today, tomorrow or sometime I still don't know." In addition, the sense of attachment with family members would cause the patients to be worried about their families and they might need an assurance that their families can still live without them. As a result, the patients prepare for the death.