CHAPTER 6

FAMILY MANAGEMENT IN PROVIDING LONG-TERM CARE FOR STROKE SURVIVORS

Changes from having a permanently disabled family member lead to family management in providing long-term care for a stroke survivor at home. This chapter describes family management, which is divided in to three parts: adapting the home environment, learning to live with caring for the survivor at home, and taking care of the family's health.

Part 1: Adapting the Home Environment

"Home" was viewed by all participating family members as the best place for long-term care of stroke survivors. Thus, the families adjusted the home environment to look after stroke survivors at home by rearranging the bedroom and bathroom and also providing some necessary equipment to ensure convenience in performing home care.

When a stroke patient returned home, all families in this study, extended families and nuclear families alike, perceived that home was the best and the most suitable place for providing long-term care of stroke survivors because of the atmosphere of love and warmth, and the presence of offspring and relatives, as demonstrated by participating families:

> She (a stroke survivor) came back (from a private hospital) to our home. It must be better than in the hospital because of fresh air, full attention, and rest. Because of all these, the patient's psychological condition gets better. It is better and more appropriate than staying at other places. … (The thirteenth family)

> … We never thought of …(a name of a nursing home the stroke survivor used to stay). There is a relationship in our home. She (a stroke survivor) said that she wanted to go home. We just only thought of our home and never thought of other places else. … It (a nursing home) seemed like a mass product. They provided routine care, which was differed from care at home. It was not different when it came to, but at home we could offer a better care. (The twelfth family)

Additionally, family members shared the same opinion that the family members were able to take a complete and quality care of the survivor at home. Thus, home was the place to offer better care and safer environment for stroke survivors than healthcare centers.

> Home is the most appropriate place for any patient who has the same condition as our mom because we can take care of her closely. In the hospital, there are more than ten patients in a ward but only a few nurses who are responsible for caring for them. They may not be able to give a complete care to the patients. Mistakes and risks such as errors in giving medication may easily occur. But at home, such incidents do not occur because we attend only to my mom and the caregiver is no one else, but her own daughter. (The first family)

Consequently, due to the family's belief that home was the most suitable place for long-term care of stroke survivors, all family rearranged the home environment to provide a long-term care for the survivors at home. The home environment, particularly the bedroom and bathroom, included physical features such as the housing materials, structures, and special equipment that had to be modified to support continuing recovery and ensure safety of the survivor. All these modifications were done according to the advice the families received from the nurses or physicians before the survivors returned home. However, the families also adjusted their home environment by make their own consideration and decision as to how it should be changed. In most of the participating families' houses, the bedroom, toilet, and ground floor were adjusted to make it convenient for providing proper care, lifting and moving stroke survivors, and also to ensure safety when performing some activities. Due to the stroke survivors' difficulty in movement and needs for 24-hour care, almost all families modified the first floor of their home to be the survivors' bedroom, except the tenth family that put the stroke survivor on the second floor because of the limitation in space:

> He (a stroke survivor) used to sleep on the second floor. After he got a stroke, he was unable to go upstairs. Thus, in order to ensure convenience, we have to move his bedroom to the first floor by redecorating my bedroom and turning it into his bedroom. And we also constructed a bedroom nearby to be my mom's bedroom because it is convenient for her to take care of him (a stroke survivor) … (The second family)

> He (a stroke survivor) lived on the second floor when he was healthy. But now he is different because he has difficulty walking. He tried to walk to his bedroom upstairs, but it was so difficult. We decided to set this area (a space on the first floor) to be his bedroom in order that he does not have to go up and down the stairs. (The third family)

> … We already know that she (a stroke survivor) cannot walk and go upstairs (after having a stroke), but my home is a row house. Initially, we planned to arrange a room on the first floor to be her bedroom, but it was impossible because, as you see, this is (the first floor) used as my office. We moved her to live in some places else, such as my friend's houses. After that, I discussed this with my mom and we agreed to modify the second floor to be her bedroom. She (a stroke survivor's mother) agreed because even though she lives on the second floor, she cannot walk. (The tenth family)

Adapting the bathroom was also mentioned by participating families to ensure the survivors' convenience and safety. This adjustment was done in two ways—building a new bathroom in the survivors' bedroom and modifying an old bathroom the family used to have. Some families built a bathroom or a toilet in or near the survivors' bedroom and also installed some equipment for the survivors' convenience. For example, the first family built a bathroom in the survivor's bedroom. The family members said *"It was intentionally constructed because of her movement difficulty and our convenience when taking her to take a bath."* The second family also put an old-styled floor-sitting toilet nearby the survivor's bed. The family members explained, *"Initially, we did not put it like this, but we faced a problem that he could not move and we could not help him get to the toilet immediately when he felt a necessity to evacuate the bowels. Therefore, we put a toilet on that (near the top of the survivor's bed) to solve the problem."* For most of the families, however, they reconstructed the bathroom the family already had. Some families replaced an old-styled floor-sitting toilet with a modern toilet seat so that stroke survivors who could still move to sit on it more easily. They also installed side rails for the survivor to hold on to. Other families modified some accessories with the old-styled floor-sitting toilet in the bathroom. For example, the third and fourteenth families cut out the seat of a wooden chair which was commonly used in a classroom and put a toilet seat on it. When the survivors needed to go to the toilet, the caregivers put it over the old-styled toilet because it was easier for the stroke survivors. Additionally, the surface of the floor was fixed with non-slippery tiles to prevent stroke survivors from slipping or falling down. They constructed a slope so that they could take the survivors in the wheelchairs to the toilet as well.

> … We reconstructed the bathroom because its door was too narrow to push her wheelchair through and the floor was slippery. So, we used non-slippery tiles as the bathroom's floor and widened the door so that we could take her in (a stroke survivor) to take a bath in a wheelchair. (The eighth family)

In addition to rearranging the bedroom and bathroom, the families also provided necessary appliances for stroke survivors, which were in accordance with the survivors' conditions. Some appliances were rearranged according to nurses or physicians' advice, while others were rearranged as the families thought appropriate. The appliances commonly found in most of the families were the hospital bed, walking and moving appliances such as a wheelchair, a cane, and a walkers, as well as equipment for elimination such as a urinal and bedpan. Seven families used hospital beds for stroke survivors. They thought that the bed made it more convenient for them to take care of and move the survivors, especially for six survivors who were complete dependent. Instruments for elimination and walking or moving appliances were generally found in the survivors' bedroom because of the survivors' movement difficulty. Besides, there was simple exercising equipment located at some sites in the house such as parallel bars, which were made of iron or bamboo and a simple pulley with rope on two sides. Survivors with complete dependence in the first, fourth, seventh, and eleventh families needed other complex equipment. Therefore, a suction machine and a home oxygen therapy were found in these families' homes.

However, participating families pointed out that the family's economic status was an important condition determining the adjustment of the home environment of the family. The families which were more well-to-do, such as the first, seventh, eleventh, twelfth, and thirteenth families, perceived that their high economical status enabled them to afford home adjustment and other equipment necessary in looking after their stroke survivors at home. They redecorated specific rooms with some facilities such as an air–conditioner, television, and radio for stroke survivors. One of these families said, *"Because our family can pay for it, we pay for everything that is necessary in taking care of the patient at home."* These families also bought all new medical appliances and equipment which they thought were necessary for the survivors. For six bedridden stroke survivors in rich families, family members put alpha-beds on top of the bed to prevent pressure sores. By the same token, low income families perceived that financial difficulty of their families was an obstacle in adjusting their home environment and providing some needed medical appliances. The third family, for example, simply arranged an area downstairs in the house for a stroke survivor, using a curtain as a partition and putting an old wood bed for the survivor and his wife. These families with a low economical status also tried to provide only very necessary appliances by borrowing them from the hospital and temple or asking for these items from other families whose care receivers already passed away, including a wheelchair, walker, and cane. As for other appliances which could not be borrowed such as urinal and bed pan, they bought them and/or adapted old materials in their house such as the toilet seat, as could be seen in the third and fourteenth families.

Part 2: Learning to Live With Caring for the Survivors at Home

Moreover, families had to learn to live with prolonged caregiving for stroke survivors at home including adjusting the family's way of life, living with and managing stressful situations in the family, dealing with family finances to overcome financial burdens and organizing family roles and function accordingly.

Adjusting the Family's Way of Life and Living

All families stated that they had to adjust their usual daily life in order to live with caregiving for a disabled family member at home so that the stroke survivors' needs became most important. Family members adjusted their patterns of sleeping and rest, working, joining social activities, and exercising according to the survivors' activities of daily living. Some families adjusted their plans after many years of caring for the survivors.

Participating family members focused on adjusting their resting and sleeping patterns including time and place to be able to provide close care, perform care tasks for stroke survivors, and do their own daily activities. This adjustment was related to the level of dependency and care activities required by stroke survivors. As for the survivors who needed to be totally or considerably cared for, their families' resting and sleeping patterns were obviously adjusted. The first, fourth, and seventh families, for instances, had to provide tube feeding and a bed bath for their stroke survivors. Therefore, they had to go to bed late at night and get up very early in the morning. They spent time whenever the stroke survivor rested for their own rest:

> … As for changes in my sleeping pattern, I've slept with my mother (a stroke survivor) since she got sick to take care of her. My father said that it is good to sleep with her because I can take care of her if something happens at night. (The twelfth family)

> I sleep with her (a stroke survivor) in this room to provide 24-hour for her. It makes me feel rest assured to be near her. I often wake up in the middle of the night to look at her, to see if she has urinated or something else… I wake up earlier than I used to in order to prepare her food and give her a bed bath. (The first family)

Some families, particularly those originated in Chiang Mai, mentioned that they changed their sleeping place because of a cultural belief. According to them, they had been taught that children should not sleep higher than their ill parents. Thus, they followed this teaching without understanding the real underlying reason, as members of the third and the ninth families stated:

> I do not know either. All I know is my mother told me that I am a daughter, so I cannot sleep higher than the parents, particularly when he (a stroke survivor) is sick. People took this seriously, so I moved to the room downstairs. (The third family)

> We slept downstairs. … I believe that the parents must sleep higher than us. It seemed to be odd, if I slept higher than them. Northern people believe so. So, we

> moved to sleep downstairs when he got sick. … Now even though we sleep upstairs, he (a stroke survivor) sleeps higher still. He sleeps on the bed, but I sleep on the floor. … (The ninth family)

Furthermore, care for stroke survivors at home led many families to the decision to modify their type, time, and/or place of work to be able to take care of the survivors. For example, the wife of the stroke survivor of the second family changed her occupation from selling foods at the restaurant to her house after she took care of her husband. She reconstructed a booth in a small area in front of the house to sell food. With this change, she could take care of the survivor whenever she wanted. Similarly, in the third family, the wife of the stroke survivor sold food by riding a bicycle around the community after her husband got a stroke. She said that it enabled her to care for her husband any time she wanted. Likewise, the daughter of the stroke survivor of the sixth family rescheduled her work from Monday to Friday to overtime work on weekends because she had to be home and prepare meals for her father who got a stroke. She explained:

> …I used to work in the morning and returned home in the late evening. After my father has a stroke and stays with me at this house, I have to work in the daytime and take care of him, too. How can I do it? So, I come home at noon and in the afternoon everyday to prepare food for him. Some days he has breakfast until nine o'clock. So, I am late for work, but I also work on Saturday and Sunday. (The sixth family)

The eldest daughter of the stroke survivor in the fourth family, for example, also rearranged her work from working outside to working at home:

> I had been a teacher of a non-formal education institute. After my father got a stroke and needs total care at home, my mother takes care of him solely. I want to

> help her care for him but if I was still a teacher, it was impossible to do so. Therefore, I changed to sewing at home. It is flexible for me and I can take care of my dad and do some household chores. (The fourth family)

Participating families also adjusted their social life. The stroke survivors seemed to be the center for their planning for family outdoor activities. They managed their social activities by arranging indoor activities to be done together with stroke survivors and joining outdoor activities with other people without stroke survivors. Most families spent more time to perform some activities together at home instead of going out. For instance, the fourth family used to enjoy making merits at temples and going to other provinces. After caring for a stroke survivor, it was tough and difficult for them to take their complete dependent stroke survivor anywhere with them. As a result, to maintain the family social activities, they changed to making merits at home, instead of taking him to the temple. Similarly, the second family celebrated the Songkran Festival together at home instead of taking a trip to other provinces as they used to do. The offspring came together at home to pour perfumed water to pay respect and asked blessings from their parents. Also, the twelfth family created “a family day” as their own tradition after long-term care of a survivor at home.

> Sunday is our family day. Everyone realizes that we have to get together and have something to eat such as Pizza or KFC or ice cream on Sundays. We all get together every Sunday and we have done this regularly for many years after my mom got sick. She is very happy that everyone is here, and so am I. (The twelfth family)

As for managing family social activities without stroke survivors, all family stated that there was one person who stayed with the survivors at home to take care of them. Moreover, the activities the families participated were considered to be really important and the places were not too far from their home. The families also spent free time from care tasks on social activities. As regards arranging someone to stay with stroke survivors at home while other family members joined outdoor activities, the families stated that they were concerned about the survivor and could not let them stay home alone. Thus, they arranged one family member who was close to the survivor and who was able to take care of the survivor to stay with him/her. In the second family, for instance, the fifth son had to do caring activities and stay with their stroke survivor while other family members performed outside activities. This was the same as the ninth family, as the survivor's wife joined religious activities at the temple near their home on every Buddhist day. Her son got up early to take care of the survivor instead of his mother when she went to the temple:

> She (the survivor's wife) has to offer food to the monks at the temple every Buddhist day. So, I wake up earlier to prepare breakfast for my dad (a stroke survivor), while my mom goes to the temple. Sometimes, she wants to go with her friends or goes see the doctor, and I stay with my dad and let her go. … (The ninth family)

Some families managed their social activities by taking the importance of those activities into consideration as the eighth family stated:

> We have someone in our family living with my mom (a stroke survivor) while others go outside. Moreover, we join outdoor social functions particularly the ones which were considered to be important such as cremations of our close relatives. … (The eighth family)

Additionally, some families also spent free time from care tasks to perform some social activities. However, they were complete activities for the survivors before going out.

The first family, for example, spent two hours during feeding times to go out for lunch, exercise with neighbors at the public park, and buy some fruits at the market.

Besides, when caregiving became a long-term task of the families, many families had to revise their living plan in the future as they realized that with a stroke survivor under their care, it would be impossible to accomplish their plan. One example came from the fourteenth family whose family member stated that her husband and she bought a garden and built a small house there as they planned to do some farming and live a simple life when they got older. When the husband got a stroke and became a disabled person, the wife gave up their plan and let the garden desolated and the home run down. Similarly, the ninth family had a garden with a small house and a lot of plants. They sometimes spent their free time at that garden and planned to make it their permanent home in the future. This plan collapsed after some years of caring for the stroke survivor. The garden was sold after the fifth year of care. Also, long-term caregiving reduced an opportunity to follow life plans of the tenth family as a family member shared their life experience:

> I once planned that I would continue working for only two more years, and I would have enough money to expand my business. I thought it would be better to get a loan from SME and buy printers. But, you know, when she (a stroke survivor) has a stroke, I cannot think further, because it is an investment, a big investment! I cannot do that because I have to prepare my money for our mom and sister (a stroke survivor). They (a stroke survivor and mother) are my responsibility, and I just have to plan for them now… (The tenth family)

Additionally, providing long-term care caused families to make a new plan for the future in case unexpected events occurred to stroke survivors or other family members. Many families were worried and feared about what would happen if they or other members of the family passed away before stroke survivors, became ill, or were in need of care some day. As a consequence, they prepared themselves in case the worst ever happened to them:

> I think my sister would not last long. It is good for us that we can plan ahead, if something happened to her. … I started to plan… I prepared a formal dress, a funeral memorabilia, and others. I then called the hospital and asked the staff what we should do if someone died at home. I also asked for the price of the coffin. I now know all and am ready for the approaching death. (The tenth family)

> If I am alive, I could take care of everybody, but what if I pass away before them? This is the most important thing I am worried about… This is my thought, and the truth is that I am not worried about my daughter. I need their care, and I told them that if something happens to me how much she should give her mother and her (caregiver's name). I have given her my instructions. (The thirteen family)

Managing Stressful Situations in the Family

Long-term care for stroke survivors at home was perceived by all participating families as an extremely stressful family life event because of many changes in families' life. As a result, families managed their stressful situations by creating good atmospheres in the families including using humor, positive thinking, and mutual encouragement. Furthermore, when confronting conflicting situations, they overcame them with explanations and reasons to avoid and prevent these situations from becoming serious.

Besides, most families perceived that caring for a disabled family member for a long period of time was a stressful event for their families because they encountered various changes in their life. Therefore, using humor was one of the ways the family used to manage stressful life events. They explained:

> I feel disturbed as a result of attending to her (a stroke survivor) because I have to do so many activities. I always complain and my husband knows how I felt. … Every time he listens to me, he says nothing. He just laughs. When he laughs, I

> feel better. … Ever since we started living together, we have always used humors to make us laugh. Everyday there are jokes to make us laugh. We have no tension, and we have a good atmosphere in the family. We experience no tension even if we have to take care of a disabled mom. (The eighth family)

> I am a humorous person, as well as my sister-in-law. I personally am not serious or easily upset. If I am easily stressed, I would be in big trouble, particularly when we have to provide long-term care for him (a stroke survivor). Now, we have daily jokes to make use laugh. It helps us a lot to reduce stress. … (The sixth family)

A few families learned to think about providing long-term care for a stroke survivor at home positively by comparing themselves with others. For example, the fourth family indicated that even though they had provided care for the bedridden survivor for many years, they were still luckier than other families whose members passed away from a stroke. They said that they still had a loved one in their family. This thinking nourished the family and made them live with less stress.

> Every time I look at him (a stroke survivor), I compare myself to many of my friends whose fathers had passed away. It lets me think that our family is so lucky to have each other—my mother, father, and he is still alive. Although he has had a stroke for a long time, sleeps unconsciously, and cannot help himself at all, but when I turn around and I see him, he is still alive. Our family still has a father. (The fourth family)

Similarly, the ninth family thought about long-term care for a disabled family member in a positive way by means of a comparison with other families caring for a seriously impaired survivor and this helped the family feel better:

> Whenever I compare my father (a stroke survivor) to other serious stroke survivors, he is still better. My positive thinking is that we just cannot stop a stroke from happening such like we cannot stop the rain from falling. This makes us feel good. (The ninth family)

Besides, families expressed that the moral support they had for each other was an important factor for families looking after a family member with chronic disabilities. Such an encouragement came from members within the families and also from the stroke survivors. This encouragement was also expressed through verbal and non-verbal language. The tenth family, for instance, stated that a smile from the stroke survivor was a power to make the family be strong and have patience with the current situation of providing long-term care for a stroke survivor at home. The same sentiment was also expressed by the eighth and ninth families:

> … I tell her (a stroke survivor) to smile all the time. It is the only thing I ask from her; that is, to smile at my mother and tell her politely what she needs. I ask her not to cause my mother any trouble or do not get angry with her. … It creates my good spirits. I often tell her that. … Every time I go to see her, she smiles at me. Our family must be strong, understand each other, be in a good spirit, and be courageous. If I feel tired, my mom will know it and she will hug me and pat me on the back. It makes me feel happy, and happiness suddenly comes back to me. (The tenth family)

> I think that encouragement is very important for families caring for a family member with a chronic disability, like my dad (a stroke survivor). Everyone in our family is quite useful for one another and depends on one another. My dad used to feel hurt because of his disabilities. I encourage him, and tell him not to worry. … Once, he tried to commit suicide. … I told him to live on, as well as my mom. She

> has taken care of him (a stroke survivor) for many years, and that causes her stress. I encourage her, too, and tell her that she is doing a good deed… (The ninth family)

The eighth family had encouragement by thinking that their family was valuable because they helped the survivor get better:

> There were times when I felt depressed, because I attended to her (a stroke survivor) everyday, 24 hours a day, and I kept wondering why she still could not walk. I felt a little bit upset, but that did not destroy my intention to care for her. Now, when I think back, I can see her getting better than when she first had a stroke. I realize that if I was discouraged and gave up at that time, she might get worse than this. Maybe she would still lie in bed, and that may cause everyone trouble. I have never felt like that anymore because I know that I have intended to do everything for my mother to make her better. My previous feeling eventually disappeared. She is my supporter. (The eighth family)

Throughout caregiving, several families mentioned conflicting issues which caused the families stress. These issues were about different opinions regarding caring for stroke survivors. Families often overcame the conflicts by using reasons, explanations, and getting away from the situations, as some families stated:

> There were some problems, which were mostly about caring for my mom (a stroke survivor). We would discuss them among brothers and sisters. The ones who did not live with my mother all the time like me did not know much. For example, my mother loved to eat sweet fruits like ripe mangoes. She ate a lot of mangoes each time. I would not let her eat a lot … then I explained the reasons why not, and then everybody did not have any more words after that. (The eighth family)

Additionally, some families tried to avoid complicating the conflicts further or causing more stress than what they were already confronting by getting away from the situations. For instance, members of the sixth family described their stroke survivor continued to drink alcohol. They warned him and asked him to quit drinking because it destroyed his health but he refused to listen to them, which made the family very angry. When that happened, they went out to avoid developing more serious emotions and then came back after they had calmed down. This was the same method used by members of the third and the ninth families:

> It is quite all right to say that we do quarrel, but it is nothing serious. … But when the tension runs high, I go out of the house. If I stay, I will be unhappy. So, it's better to just leave. (The ninth family)

> … Sometimes my father gets irritated. Sometimes he gets angry because he wants other people to think the same as him. If that happens, I will not say anything. I will walk in front of the house for a while and then come back. My mom does the same. She will walk into my room when she has some problems with my dad. (The third family)

Dealing With Family's Finances

All families recognized that long-term caregiving was a source of family expenses, and the families were responsible for them. Therefore, the families reconsidered their financial status so as to have sufficient funds by increasing workloads, pooling money among family members, managing family spending, and solving family financial problems.

Increasing workloads. All participating families understood that providing long-term care for a stroke survivor at home meant long-term expenses while family income reduced. As it was their responsibility, to earn and maintain family income, most of the families increasing their workload by working harder and doing extra works.

Many families said that they had to work harder than before since they began their care for a stroke survivor at home in order to support the family's financial status. The tenth family was an example of the families working harder to maintain their financial status.

> … After her (a stroke survivor's) sickness, her agency still pays her monthly salary, but only one-third of it. You know, it is not enough for us. … I am the only one who is responsible now. I have to work very hard to take care of all the expenses in our house. (The tenth family)

Similarly, the twelfth family also worked harder to earn more income because they had high family expenses related to providing care for a stroke survivor:

> We pay a lot each month for care expenses while our income is not increased. I have my own business, and I knew that as soon as she (a stroke survivor) got a stroke that I would have to work hard to earn more income to balance our finances. (The twelfth family)

Some families got extra jobs. For example, in the fourteenth family the survivor's wife earned extra income from sewing in the evening after her regular work and on holidays. She said that after her husband had a stroke, she became the only breadwinner of the family and took sole responsibility for family expenses. With this burden on her shoulders, she had to earn extra income:

> I had trained to be a dressmaker when I was a teenager, but I did not do it to earn money seriously. After he (a stroke survivor) became a stroke patient and was unable to earn income for our family, I make a dress every evening and weekend. My colleagues know that and they give me money to make dresses for them. It is my extra income to support the family. (The fourteenth family)

Pooling money among family members. The family members perceived that family finance was "their" responsibility, not anyone person in particular, so almost all families experienced sharing with and helping one another, whether they lived in the same house or not. They regularly gave money and were willing to be involved in helping with the family expenses as much as they could. For example, in the second family, the survivor's daughter described a "Go Dutch" strategy of equally paying the same amount for household and the survivor's expenses. In the third family, the daughter and son-in-law gave their financial support constantly even though they had a low income. They explained that they were part of the family, so it was right for them to lend a hand since their father (a stroke survivor) could not earn any money for the family. Several families, such as the second, the fourth, the fifth, the sixth, the eighth, and the eleventh families gave financial assistance instead of directly taking care of the survivors. Some of these families reported:

> We all share the costs. Our family has many siblings, and everyone contributes to the family. Nobody is unwilling or refuses to give money to share the burden. Everything is fine because we think that we are members of the same family. There are no problems as long as we help each other. (The eleventh family)

> He (a survivor's son) cannot take care of him (a stroke survivor) because he lives with his own family in another district, but he intends to participate in family financial situation. He knows that care for our dad (a stroke survivor) means a lot of expenses, so he has given money every month since our father had the stroke.

> He often tells us that he knows how much money he (a stroke survivor) uses monthly. He pays instead of taking direct care. … (The fourth family)

Likewise, in the fifth family, the survivor's daughter could not care for her father directly because she worked and lived in Bangkok. Therefore, she sent money, around 2,000-3,000 baht, every month to help cover the family's expenses. Moreover, when her father required extra money, she gave him regularly as much as she could. For the sixth family, the stroke survivor had four adult children. Some of them lived in the same house, while others lived in other places. However, all of them still helped each other with financial support and shared family expenses. The stroke survivor's son who was a monk regularly gave money for family expenses, while the stroke survivor's sister and daughter-in-law shared the utilities bills.

Managing family spending. Many families tried to manage family expenditures after taking care of stroke survivors because they knew that it was a long-term care than cost a lot of money. All of the families perceived that expenses for the survivor's needs were more important than other family members' needs. As a result, families set a plan for spending, especially for the stroke survivors' expenses, and minimize other unnecessary expenses.

Throughout many years of care, the second family, for example, set a plan for spending, by precisely allocating money for each kind of expenses. They arranged money given by the son for utility bills, and saved the reimbursed money from the government only for the survivor's next medical expense. They said, *"If we do not manage family spending systematically like this, we will have to face a financial problem. Especially, we may not have enough money for his (a stroke survivor) medical expenses each time because we have to pay around 5,000 baht every two months for his medications. Setting a spending plan like this allows us to handle family expenses."* Similarly, the fourth family divided their income for different family expenses. They explained that they had to save the money because they had spent a lot of during the four years of caregiving and it would continue if the survivor was still alive. Thus, they arranged family spending by saving the apartment rents particularly for buying instant blenderized diets for the stroke survivor and the revenues from their grocery store for the family's daily living expenses.

Many families also managed family spending by minimizing unnecessary expenses. Some of them indicated that they thought carefully before paying for anything and considered whether it was reasonable to pay or not, as one described:

> In the past, I bought anything I wanted, like other teenagers, without too much thinking. But now, I have to be more careful and think before buying. I must think that if I buy it, I might jeopardize my family's finance. So, I plan my spending because I have at least two lives under my responsibility now. (The tenth family)

> We don't know how long we will have to take care of her. Now the cost of living is getting higher, while our income is limited. Even though it is not a problem now, saving is the best way not to face that kind of problem in the future. Now, we spend only on things we consider necessary. … (The twelfth family)

In addition, many families searched for low-price resources of supplies for the survivor in order to minimize care expenditures. Members of the tenth family stated that the stroke survivor had to use around eight pieces of diapers per day, so the family tried to save money by buying directly from the manufacturer. It was two baht cheaper than those sold in a retail shop. Likewise, the seventh family sought for the place where they could pay less for plastic sheets, as the stroke survivor's wife said:

> … a lot of money must be spent for the stroke survivor in the long run and no one knows how long it will last. Thus, it would be better to save when we can. For example, we spend a lot of money for plastic sheets because he (a stroke survivor)

> uses many of them a day. Now, we can save after buying from a low-price shop. (The seventh family)

Several families, such as the second, the sixth, the seventh, the eleventh, and the fourteenth families got assistance for medical costs from stroke survivors' employers and the national government health security benefits (the 30-baht universal healthcare scheme). These families said that this assistance was useful for them because it reduced family expenditures related to care. They reimbursed for all expenses they could such as medications and paid for other things which could not be reimbursed such as an alpha bed, plastic sheets, plastic diapers, feeding tubes, suction tubes, instant blenderized diets, and disposable gloves:

> I claimed the stroke survivor's medical costs that could be claimed. For additional costs related to the care such as a bed, an alpha bed, and a wheelchair, we paid for them by ourselves. It is good when the government helps us, and the money is for taking care of him (a stroke survivor). (The seventh family)

> She (a stroke survivor) receives a pension and support for medical costs. …It is not much, but it does help us. At least it covers her medications. … If I don't get it like this, it would be a problem. … (The thirteen family)

Solving family financial problems. Due to decreasing family income and increasing family expense as a result of providing long-term care for stroke survivors, some families faced financial difficulty. To deal with this problem, these families used their savings and sold their belongings or properties. If these methods were unable to solve the problem, they asked for financial assistance or borrowed from other persons. The ninth and fourteenth families shared their experiences:

> I helped him (a stroke survivor) work when he was still healthy, but after he fell ill, he couldn't work anymore. My mom used our savings for our living. In the fifth year of his sickness, we had to sell our belongings to earn money for his treatment and for daily expenses and food. We didn't have any choice as my parents couldn't work. (The ninth family)

> When he (a stroke survivor) was healthy, he always drove to pick some crops like mangoes and vegetables to sell. … But after he becomes ill like this, the car is unnecessary for me because I can't drive. More importantly, we need money for our daily life and his treatment. Our savings were spent during the four-year for caring for him, so I decided to sell our pick-up truck to buy food and pay for the treatment costs. (The fourteenth family)

Some families experienced financial problems because the expenses exceeded the income. They dealt with this problem by asking for assistance from relatives or other resources to overcome their financial difficulties as follows:

> Sometimes I have less income. It becomes a problem. I borrow money from my parents. They constantly give me financial assistance. They say that it's such a struggle for me to earn the family income alone while I have so many expenses. They give to me whenever I ask. (The fourteenth family)

> … Yes! We have a financial problem sometimes because we have used all of our savings to take care of him (a stroke survivor). My mom asks for help from our relatives and sometimes, from our neighbor. … (The third family)

Organizing Family Roles and Functions

To provide care for a disabled family member at home, all families had to reorganize roles and functions in the families. Families had to play the role of family caregivers of the survivor and also carried stroke survivors' previous roles and functions in the family.

Playing the role of family caregivers. The changes following a stroke impacted the survivors' ability to perform activities. Every family stated that when a stroke survivor returned home and needed care by others, they perceived that it became a task of the family to take care of him/her. They believed that families had to look after ill family members due to feelings of love, sympathy, concern, as well as sense of duty. Thus, all participating families had the willingness to play the role of family caregivers.

Playing the family caregiver's role was presented as "a team of care" because many members in each family took part in this task. It could be described that there was at least one member of the family who became a primary caregiver who performed daily activities for stroke survivors, and this tended to be a female family member, stroke survivors' dyad, or children, while other family members offered support or participated in various kinds of care tasks including contributing money, information, foods, or other materials. Every family explained that becoming a primary caregiver was automatic, with the wife took care of her husband with a stroke, and adult children, mostly daughters, took care of their stroke parents. These primary caregivers had a close relationship with the stroke survivors and were able to spend their time with the survivors, as evidenced below:

> … I willingly became the main person who helps her with daily activities because she is my mother and is very close to me. Now she is sick, so I have to look after her. … For me, I give her a bath, help her exercise, and help her with urination and bowel movement. My older sister feeds her and gives her medications. Moreover,

> my husband also helps us although he doesn't provide direct care, as he often buys plastic sheets, instant diets, and pays her a visit. (The first family)

As for such extended families as the second family, family members played the role of family caregivers. The stroke survivor's wife was a primary caregiver who mainly took care of personal hygiene, doing laundry, and preparing foods. The eldest daughter helped her mother take care of her father in the daytime, particularly when her mother sold foods in front of their house. The fifth son was a person who accompanied the survivor to see the physician, did exercises, and also gave the survivor a bath on his wheelchair twice a week. Other family members often visited the survivor and brought him foods.

Of these 14 families, there were two families, the fifth and the twelfth families, whose family members could not take care of their stroke survivors by themselves. Therefore, the families hired a person to be a primary caregiver of stroke survivors while members of the family helped in some activities. The reason for hiring was different. For the fifth family, family members said that the stroke survivor was a male and divorced, while other family members were female (older sister, sister-in-law, and niece). They thought that it was inconvenient to provide care for a stroke survivor who was male. In addition, they thought that a male caregiver was stronger than female and that he could carry or support the stroke survivor better than they did:

> There are only females in our house, so I don't know how I could care for him. I can't because I am female. … We discussed it and decided to hire a person, a male, to be his primary caregiver. We thought that he had a lot of strength, so it would be easier for him to carry and support the patient who had movement difficulty. (The fifth family)

The twelfth family was a nuclear family composed of three members—the husband of the stroke survivor, the son, and the stroke survivor. The husband worked and the son studied during the day. Both members of the family could not be a stroke survivor's primary caregiver, so a primary caregiver was hired to do caregiving tasks. The family members helped and did some activities:

> … I know that her condition (a stroke survivor) needs someone to perform 24-hour care. There are only the two of us at home. We have no one to look after her (the stroke survivor). Really… I have to go to work and my son has to attend school. Even though he did not go to school, he could not be fully responsible because she (a stroke survivor) could not help herself. When we moved her (a stroke survivor) back from the hospital, we hired a person to take care of her at home. (The twelfth family)

Substituting roles and functions of stroke survivors. Participating family members had to take over stroke survivors' roles and functions in the family because the survivors were no longer able to do them. Some or all of these roles and functions were transferred to other family members. For example, in the second, third, fourth, seventh, ninth, and fourteenth families whose stroke survivors were husbands, roles and functions the survivors had performed went to their wives. According to a family member of the thirteenth family, there were three members living together in the same household. When the wife had a stroke, both her husband and the remaining member shared previous duties of their stroke survivor. He stated that he divided the stroke survivor's former duties with his niece. Similarly, the fourth family substituted the survivor's roles and functions in the family because of his complete dependence. For example, the survivor's daughter and wife became a decision-maker of the family and the daughter purchased goods for the store.

Additionally, family members of the twelfth family stated that the stroke survivor used to perform the mother's roles. She took care of her son such as preparing food and sending him to school and picking him up after school. She was also in charge of the family's daily life. After she had a stroke, she could not perform those duties at all.

Some of her previous duties went to her husband, while the others were transferred to other people. The survivor's husband said that he had taken over a mother's role since his wife got a stroke. He also paid for a housemate to do household chores.

Some participating family members had to perform legal activities on behalf of the survivors. For example, in the twelfth family, the husband of the stroke survivor took care of all legal matters such as transferring of the ownership of the assets that belonged to the stroke survivor. In the tenth family, the survivor's younger sister was responsible for all documents on behalf of her stroke survivor. She printed the survivor's fingers, then certified that it was the fingerprints of the survivor's right hand, and arranged for her younger sister to do the documents and legal works. Also, in the thirteenth family, the husband of the stroke survivor signed the survivor's signature on her behalf when contacting the government services. He showed the researcher the signature he signed and the one she signed on her ID card, and they were identical. He explains:

> She used to be involved in our business. Most of her duties were related to legal matters. After she got sick, she can no longer do it. I had to transfer all of her works to be my works. If I didn't do that, our business would be affected. (The twelfth family)

> … I sign her (a survivor's) name when I contact the bank and her previous organization. The bank staffs know that she cannot sign or write because of her physical disabilities, so they allow me to do that on her behalf. (The thirteen family)

Many family members mentioned that sharing the family's roles and functions was done without taking gender into consideration. However, for some works, gender still needed to be taken into account, particularly those related to custom and cultural beliefs. Some native families mentioned religious practices the stroke survivors used to perform, such as worshiping the spirits of their ancestors that female family members should follow:

> We pay respect to our ancestors' spirit. We must worship them. It is unavoidable. Before this, my mother (a stroke survivor) worshiped them every year. After she had a stroke and could not do it, I have done that instead of her for two years now. I know that only female family members, who are the daughters of the family, should do this, but I don't really know why. (The eighth family)

> Our father passed away over ten years ago. We always pay respect to his spirit. Our mother used to perform that, and she offered foods and desserts to the spirit house. She cannot do it now because of her stroke, so it is me or my younger sisters who worship my father's sprit and offer food to the spirit house. (The eleventh family)

Overall, participating family members rearranged their family life to look after the permanently disabled members at home because they realized that home was the best place for long-term survivors to be. To provide long-term care for stroke survivors at home, families managed their lives by adjusting the home environment, particularly the bedroom and bathroom, and provided medical appliances for the survivors. Moreover, families learned to live with caregiving for their survivors at home. They adjusted their usual daily life so that they could take care of the survivors at home, managed stressful situations in the family, dealt with family finances to balance family income and expenses, and maintained roles and functions in the family.

Part 3: Taking Care of the Family's Health

Caring for health of all members in the family was perceived as one of the family's roles. However, at first every family gave their first priority to taking care of stroke survivors because the survivors were seen as patients, not normal persons. All families provided care to ensure the survivors' physical and psychological well being to suit the stroke condition. After a prolonged period of care for a stroke survivor at home, the families began to pay attention to the health of the family. Primary caregivers' health received the most attention because their health deteriorated as a result of provision of long-term care. Meanwhile, other family members took more care of themselves as they had realized that they were an important component of their family.

Providing Care for Stroke Survivors' Health

Becoming a disabled person as a result of a stroke reduced stroke survivors' abilities to perform activities in their lives. Their psychological health was also affected. Therefore, they required care for both their physical and psychological health from their families. All families mentioned that they had to learn to provide suitable care for stroke survivors at home including care for daily life activities and psycho-social health, as well as care for the stroke condition.

Learning to take care of stroke survivors at home. All participating families stated that they had to learn to care for disabled family members throughout many years of looking after them. Prolonged care let the family know that they were not completely prepared to provide long-term care at home. Many families described that they used the 'learning by doing' strategy, applied their previous experiences, and searched for more information by themselves or by consulting others. All of these enabled them to understand how to do proper caregiving activities for the stroke survivors and solve problems related to provision of care.

Learning by doing and applying previous experiences were commonly mentioned by families. Among participating families, some stated that they had formal training for care at home from nurses before the survivors were discharged from the hospital. Tube feeding, preparing blenderized diets, and/or utilizing rehabilitation methods were among the activities the families received formal training. However, the training they received turned out to be insufficient because they still faced problems when they actually became caregivers at home. To be more specific, some procedures were not suitable for caring in their real situation at home, while others were not mentioned by nurses and physicians. Thus, families who provided long-term care for stroke survivors needed to learn how to perform proper care in their real-life situation and to solve or prevent problems related to care. For example, the first family shared their experience with troubles with the equipment and schedule of tube feeding because they thought that they had to continuously tube-feed the stroke survivor six times a day just like in the hospital. After six months of doing so, they tried to change the feeding method and schedule to overcome the trouble. They finally found the most suitable feeding method for their stroke, which was giving 50 ml of the diet with a syringe and waiting for five minutes before resuming until the stroke survivor got 250 ml of the diet. Feeding times were also changed to be close to meal times of ordinary, healthy people. Similarly, the seventh family adjusted the food preparation procedure and applied some tools in the house to be used after facing a difficulty preparing blenderized diet for the stroke survivor. According to this family, in the first few months, they spent almost all day preparing the diet. Finally, after trials and errors, they prepared blenderized diet by cooking once a day, dividing the diet for each meal, and storing each meal in five small bottles in the refrigerator. They warmed it up in a microwave oven before each feeding. This method was convenient, safe, and less time-consuming.

The family also indicated that during care for their stroke survivors they realized that some materials and appliances were unnecessary and wasteful, such as plastic sheets, diapers, and gauze pads. Consequently, to save money and reduce the waste, they made adjustment. For instance, the first family folded unused clothes into small square pieces and used them with plastic sheets to collect urine. They found that it helped them save money and reduce the quantity of garbage each day. More importantly, this method made the survivor’s skin dry because her urine did not turn run back to her buttock. By the same token, after the fourth and seventh families observed that the survivors voided only on half of a plastic sheet, they cut clean parts into small pieces and used them with a new plastic sheet to collect feces and urine of the stroke survivors. After the stroke survivor had bowel movements or urination, only those small pieces would be thrown away. This helped them save money and reduce the amount of waste. Besides, many families modified rehabilitating equipment based on the Thai wisdom. The eighth family used bamboo to construct double rails for the survivor to practice walking. The twelfth family also made exercise materials for the stroke survivor by attaching a basket containing small stones to a pulley for the stroke survivor to pull. If more weights were needed, they put in more stones, but if it was too much, they just took out some stones.

Additionally, almost all participating families indicated that they had to learn to communicate or understand the survivors' expressions due to their difficulty in communication caused by a stroke. Among all of the survivors, four survivors could not speak, while the other ten could. Only three of these ten could communicate almost like ordinary people, while the others had difficulty speaking. The initial stage of caring seemed the time of frustration for the families because they could not understand what the survivors were trying to tell them. Families said that it took them a long time to learn to communicate and understand the survivors' expressions. Thus, family members who spent less time with stroke survivors would not be able to understand the expression well when compared to those who spent longer time. Besides, words alone were not adequate to convey meanings sometimes, and non-verbal language such as facial expressions, gestures, and special signals or signs were developed when spoken words alone were not enough to ensure mutual understanding and communication. For instance, as for the first family, when the survivor seemed to be uneasy, it meant that she had urinated. They would then clean her up and change her clothes. The tenth family communicated with the survivor by letting her lift her right hand up and down and raise her voice. The mother, who was her primary caregiver, easily understood such expressions and could respond to the survivor's needs correctly:

> …Though she only sleeps and cannot help herself, her facial expressions of anger and hurt are easily understood. Her face twitches as if she were crying when she is hurt. Sometimes I run to give her a big hug. If she feels uneasy, then her face turns

> ugly and unhappy. She looks happy after shampooing and having her hair dried. She turns left and right very fast, and this clearly indicates her expression of liking. It took time to learn to understand these expressions, and they became known due to actual caring of her. (The eleventh family)

Furthermore, all families also seek knowledge to provide stroke-related care and solve problems. They searched for knowledge from scholarly sources by themselves and consulted with healthcare personnel, which improved their understanding of what stroke was or what was happening to their survivors. The first family was a clear example. The family often discussed with a pharmacist about effects and side effects of medications taken by the stroke survivor. They also developed clear understanding of the pathology of stroke through their discussion with physicians, from self reading, and from previous caring experiences. Their stroke survivor had symptoms of respiratory infection that caused her to be hospitalized. Therefore, the family learned to minimize the severity of the complication that might cause her to be hospitalized again. Whenever she started to cough with secretion, they had to give her antibiotics immediately after consulting the physicians and/or pharmacists. Another example is the twelfth family, whose family member said that he did not receive sufficient knowledge and information on stroke from physicians. After nine years of caring, the family had sought knowledge and information about the disease by talking and discussing it with friends who were physicians, exchanging experiences with other people who had a family member with a stroke, and searching from medical textbooks or electronic resources. This family stated that these methods enabled them to better understand the disease and provide suitable care for the survivor.

Some families consulted nurses as a way to learn to care for stroke survivors. Participating families said that they continued a good relationship with nurses in the hospitals where their survivors had been hospitalized and keep them as their resources when they needed help. The tenth, the eleventh, and the thirteenth families called the nurses or physicians in order to seek advice or solutions to the caring problems they faced:

> My wife always detaches the feeding tube. We have to take her to the hospital to put the tube back until I get familiar with nurses there. Now, whenever she pulls the tube out, I call that nurse to come to my house to put the tube back in. I pay her for that. I am lucky to have a network like this because I cannot solve this problem by myself. I cannot insert that feeding tube. (The thirteenth family)

> I got a problem with the feeding tube. Food didn't run down through the tube. I didn't know what to do, so I called a nurse with whom I became familiar during my granny's (a stroke survivor's) hospitalization. She gave me advice and taught me what to do. … Every time I have a problem, I call her or other nurses there and get good advice. … (The eleventh family)

Only three families had homecare nurses as their resource when they faced problems. They said that they had received home healthcare services since their stroke survivors were discharged. According to them, the healthcare team was an important source of social support, particularly when they needed solutions or advice to solve some caring problems. If they had not received the home health service, they would have been in trouble. They expressed their opinions towards the home healthcare as follows:

> The service is very good. She (a nurse) always comes to visit us and sometimes brings some physical therapist students to exercise my mother (the stroke survivor). I don't know what I should do because I have little knowledge about it and do only what I know even though I have taken care of my mom for more than a year. When they give me some advice, I just get it. … It's so good … I think it's necessary for any patient like my mom to receive homecare services and we have more time to ask homecare nurses whatever questions we may have. (The first family)

> The nurses and physical therapists would come to change my wife's feeding tube every two weeks. It's very good. They also ask about her condition and I can ask them whatever I don't understand. … (The thirteenth family)

In this study, many families sought ways to overcome stroke survivors' constipation, a common problem during long-term caregiving at home. The families such as the first, second, seventh, eight, twelfth, and thirteenth families recalled that they dealt with this problem by giving laxatives, which were prescribed by a physician, to their stroke survivors in the first period of caring. They found that it not only failed to solve constipation but also caused their stroke survivor's abdominal discomfort and disturbed sleeping and eating patterns. These families asked other families who encountered the same problems and read magazines. Finally, they decided not to use laxatives and adjusted the survivors' eating by using more natural or herbal ingredients such as fresh fruits, fruit juice, and yoghurt in every meal. Some families used natural methods such as evacuation and herbs, both in liquid and in pill forms, such as tamarind, prune juice, and orange juice. They were happy with these methods because the constipation problem was solved without having to depend on laxatives.

Care for the stroke survivors' daily living. Because of long-term physical disabilities including weakness or paralysis on one side of the body after getting a stroke, stroke survivors were unable to fully perform daily activities. Thus, long-term stroke survivors needed assistance from their families in managing their daily life activities, particularly personal hygiene and food preparation. Participating families stated that the needs for this care varied according to the level of functional disabilities of the survivors. Completely dependent stroke survivors required more assistance in their daily life than recovered stroke survivors.

In six families with completely dependent stroke survivors, performing all daily activities was the responsibility of the families. The families gave the survivors a bath once a day or once every two days, often in the late morning or in the afternoon. Many family members stated that the stroke survivors were in bed all the time, so there was little sweat. Taking a bath once a day was suitable for them. Among these families, some families gave the survivors at bath in the bathroom once or twice a week. For example, the thirteenth family gave the survivor a complete bed bath every afternoon. On every Sunday, her family members sat her up in a wheelchair and wheeled her into the bathroom for shampooing and bathing. The family members said that bathing in the bathroom was cleaner than a bed bath and made the stroke survivor feel fresh.

For the other six stroke survivors who were able to do some daily living activities on their own but still needed other care from caregivers, family members supervised, facilitated, or motivated them to perform some low-risk activities such as eating and walking. Family members always warned them to be careful about falling down while performing these activities or stayed with the survivors while they were doing them. Moreover, the bathroom door was often unlocked when the survivor was inside. However, family members still did some activities which were considered to be harmful or complicated, such as bathing, preparing meals, and doing laundry. In the eighth family, for example, a family member took her mother (a stroke survivor) on her wheelchair for a shower and brushed her teeth twice everyday in the bathroom. As for taking a shower, her daughter helped pour water over her and encouraged her to use both hands to rub her body, back and front. The daughter believed that it was a way to help her recover her hand functions. She also changed from a bar soap to liquid soap, which was easier for the survivor to use her hands. For the second, the third, and the ninth families, they still gave the survivors a shower and a shampoo. These families explained that they were still afraid that the survivors' loss of muscle strength might cause them to fall down while taking a shower and shampooing alone. In addition, it was difficult for the survivor to do these activities with one hand, so it was best for them to be bathed by their family members, as some families reported:

> She has recovered and is able to help herself, but I still bathe her because it is still difficult for her to do it, and I am also afraid that she will fall. … I bathe her in the bathroom and encourage her to use her hands. I put a soap bar on her good hand, she often dropped it, so I changed to liquid soap. That's okay. … (The eighth family)

> I think it is hard for him (a stroke survivor) to take a shower because his legs and arms are still weak. If I let him do it, he might fall down. It seems to be risky for him, so I put him on the chair in front of the house and then bathe him everyday. (The third family)

For two stroke survivors whose physical functions were recovered but who still needed assistance, their families encouraged them to perform daily activities and warned them to be careful about falling down. These families let the survivors be the first in the house to take a shower to avoid wet floors and to arrange clothes for the survivors. However, family members still washed the survivors' clothes and prepared meals for them:

> We let him (a stroke survivor) take a shower first, both in the early morning and evening because if he uses the bathroom after others have used it, the bathroom floor will be wet. I'm afraid that he would fall down in the bathroom. For other activities that he could do, I encourage him to do them but tell him to be more careful. (The sixth family)

> He (a stroke survivor) can take care of his personal hygiene. He walks with his walker to the bathroom. We only supervise and caution him. He uses the bathroom before other family members to avoid a wet floor which can make him fall. (The fifth family)

Regarding preparing foods for stroke survivors, many families modified eating patterns specifically for stroke survivors because they were perceived as patients. On the other hand, other families retained their usual eating pattern as they thought that there was no reason to adjust their eating behavior. As for eating patterns, it was found that every family whose stroke survivor could eat changed both types of foods and methods of cooking for stroke survivors. Family members prepared meals for the survivors by avoiding "fatty and salty foods" such as pork with fat, pork legs, beef, foods or desserts cooked with coconut milk, and fried foods. "Non-salty foods" were described as foods that were cooked with no or very little fish sauce or salt. Family members often prepared fish, vegetables, and fruits for the survivors based on the belief that they were good food and useful for the survivors' health, promoted bowel movement, and would not worsen the survivors' condition. In addition to "non fat and salty" food, families adjusted cooking methods to steaming, boiling, or roasting the food instead of frying. Also, they changed to use vegetable oil to cook instead of animal oil, which was high in fat content. In addition, many families that used to buy foods adopted the new habit of cooking for the survivors. Some families changed from eating glutinous rice to eating rice or red unpolished rice, as they believed that glutinous rice contained a lot of sugar. Some fruits with a sweet taste were also avoided, including durian, jackfruit, and sapodilla plum because of high sugar content, which caused complications such as diabetes mellitus and increased the survivors' body weight. Fruits such as banana, papaya, and watermelon were commonly provided by families for stroke survivors to prevent constipation.

Besides, every family mentioned "bad food" which was food that was not good for the survivors' health. Beef and chicken were perceived as harmful for health. The third and ninth families explained that the bad food caused symptoms such as itching and muscle spasm as experienced by their neighbors who lost their disabled family members after eating them. Some participating families such as the second, ninth, and fourteenth families also identified "bad food," which was extended to some vegetables such as white carrot, bean sprout, and bamboo shoot. They believed that these vegetables were cool foods, which might cause muscle spasm on the paralyzed body parts.

Three families gave more information that they modified types and methods of cooking for stroke survivors, but currently the survivors resumed the eating behavior they had before the stroke or ate as they pleased. They indicated that when caregiving became long-term, the stroke survivors themselves thought that they were in a stable condition and had no complication. This, coupled with the acceptance that they were aging, made them feel that that they were entitled to eat anything they liked during the lifetime they had left. The following account can very well clarify such belief:

> …Before he had a stroke, he ate all kinds of salty, spicy, and fatty food, which he no longer ate afterward. However, after a few years, he wanted to eat things he used to eat before. I let him do that sometimes, but other times I did not let him to. At present, his cooking and eating has returned to normal. I warn him not to eat too salty and too spicy food because it is the cause of a stroke, and the effects can be accumulated. We are afraid that he may get a stroke again. Sometimes he listens to me, but other times he does not. He said that he was bored with eating food with a bland taste, so he asks my mom to add more fish sauce and chili to make it tasty. He often says that he is old and we should let him eat as he wants. (The ninth family)

For some families such as the second, third, fifth, and twelfth families, family members did not change eating activity of the survivors much, but they tried to avoid some kinds of foods as much as they could. They also added some kinds of fruits into every meal to stimulate bowel movements of the survivors. From the researcher’s observations, stroke survivors ate foods similar to what other family members ate such as noodle topped with gravy, noodle soup, fried rice, glutinous rice with pepper sauce, spicy Thai noodle with fish curry, and fried macaroni. There were still cooking with sour, salty and sweet tastes. Most of the food they ate was bought from a store, but it was different because they asked for a mild taste variation with less salt or chili.

Care for the survivor's psychological and social well-being. Besides, all families paid an attention to the survivors' psychological and social health. They encouraged the survivors and tried to make them stress-free. Some families tried to increase the survivors' confidence by giving them compliments and telling them that the whole family was always there for them. Moreover, family members also maintained the survivors' body image by letting them dress in nice clothes or wear jewelry. As for stroke survivors' social well-being, many families encouraged their stroke survivors to participate in social activities.

Many families were concerned with stroke survivors' psychological well-being. They explained that due to stroke survivors' suffering from long-term disabilities as a result of a stroke, family members intended to make the survivors free from any stressful situation. For example, the tenth family recognized that their survivor was upset with her inability to work after she got a stroke. One day while the researcher was talking to her mother about the survivor's previous work, the survivor cried. We stopped talking. Then, her mother turned on the television and persuaded the survivor to watch a television program, which helped her clam down. The survivor's mother said that whenever she heard about her job, she was so sad and cried, so the family avoided saying anything related to her work. Furthermore, the first family often turned on the radio for their survivor, particularly programs on Buddhist teaching. Every time the researcher visited this home, a dharma program on radio was always on for the stroke survivor to listen to. Her daughter described that the survivor liked to listen to this program, which helped put her in a good mood and sleep well.

Similarly, for the third, ninth, and twelfth families, the families often encouraged stroke survivors to get involved in the families' decision making or asked them for their ideas in some family events. They explained that they did so because they wanted the survivors to know that they were still valuable family members:

> … Her (a stroke survivor's) cognition is good. She often listens to the radio and watches television. She can analyze political situations. When we watch the news together, we try to ask for her ideas. I observe that she loves to share. It seems her self-esteem increases. Also, she's good at history. Whenever my son asks me about historical issues, I always tell him to talk to his mom. She will be happy. (The twelfth family)

Several families stated that their survivors were concerned with their body image. These survivors often asked to wear some jewelry such as a wristwatch, a necklace, and a ring they loved even thought they were at home and did not go outside or dressed nicely. The families let the survivors do so, as they knew that survivors had a very good personality when they were healthy. After recovering from a stroke, these stroke survivors would like to keep their old look by wearing their belongings and dressing nicely when going out of the house. For example, a stroke survivor of the fourteenth family always put on a necklace, a watch, and a ring regularly whether he stayed at home or went out. His wife explained that her husband loved to dress with jewelry, so after he got better from a stroke, he asked to wear his necklace, watch, and ring as he used to. Similarly, the sixth and twelfth families always put nice clothes and jewelry on their survivors whenever they went out. On the other hand, it was also found that some families were less concerned about stroke survivors' image, especially the survivors who were completely dependent. Sometimes these survivors were put on a bed without any clothes to cover their lower part of the body or there wore only a diaper. When bathing, these survivors were naked as well. The families explained that since the survivors could not move, they paid less attention to the survivors' body image but more to the convenience of the families taking care of them.

As regards social health of the survivors, it was discovered that only a few families motivated stroke survivors to participate in social activities or interact with other people outside their families. For instance, the third family let the stroke survivor join some activities he wanted to such as the community elderly people's day, the Songkran festival, and local and national elections. These were a good chance for the survivors to meet and talk to his friends and neighbors. For the fourteenth family, the wife often took her stroke survivor husband on a wheelchair to the temple nearby their house to pay respect to the Buddha images. She pointed out that her husband loved to go outside because he could see the outside environment and meet his friends. In addition, a stroke survivor of the ninth family could ride a tricycle after three years of being a stroke survivor. He rode around the village to greet and talk to his neighbors everyday. His family said that it made him happy:

> He can ride a tricycle now. He rides to talk to his friends. In the first two years of a stroke, he never went out of the house. This year, we made a tricycle for him and encouraged him to ride. He loves to ride his tricycle because he can meet his friends. His happiness is clearly seen. We take him to Lotus and to some activities in our community. He is very happy. … (The ninth family)

Taking care of the stroke condition. In addition to taking care of daily activities, all stroke survivors required long-term care of the disease from their families so as to control the stroke conditions and rehabilitate the survivors' physical functions. The participating families perceived that these were a lifelong care. They had strictly followed medical treatments such as taking medications, doing exercises or physical therapy, and trying to find the methods that could promote stroke survivors' recovery. Moreover, families explained that they tried to extend the survivor's life as much as possible even though there was little chance for full recovery.

Several families shared their experience on caring for the stroke condition that they tried both modern medicines and complementary or traditional medicines, particularly in the first stage. They searched for any treatment which was not a supernatural power and which they were told or believed to be helpful for the survivors, making them get better and return to normal. If anything good was recommended to cure the disease, family members would take stroke survivors to receive that treatment. They also sought other treatments believed to be better for the survivors such as herbal compress, herbal medicines, massage, acupuncture, holy water, etc. Families stated that they spent a lot of time and lost a lot of money for these of complementary or traditional medicines, but their stroke survivors' physical impairments were still the same and nothing worked as told. Moreover, many families said that they sought knowledge about the disease, which made them understand that it was not possible to hope for fully recovery but it was possible to get better through regular exercises and modern medications. Thus, almost all families used only modern medicines as the best way to treat the stroke patients including physical therapy, exercises, and supervision of regular medication intake with correct dosage. Families also perceived that this was a lifelong care for the stroke condition, as they shared their experiences:

> I bought all good medicines as recommended by others. Even when it is as far as Sukhothai Province, I took him there. I bought medicines that others said resulted in muscle relaxation, and I bought herbs sold by vendors from Lampang Province. … Someone told us to put his feet on the grass to help him resume his walking ability, so we built a big box of grass and put his feet on it every morning. It did not work. Now, we give him (a stroke survivor) only the medications prescribed by the physician at … (name of a hospital) and do physical therapy. (The fourth family)

> There were a lot of medicines I've bought, both modern and traditional medicines such as a set of herbs (plant roots) from the south that my mother knew it was available here. I got mad with her several times because I told her not to buy them because they were useless. She didn't trust me, but she trusted those sellers. She bought everything that was recommended as good, including food supplements and

> medicines. Regardless of how far it was, she would go there to buy it for my dad with the hope that it would help him walk again. She bought every kind of herbal medicines—both in tablet forms and in original forms that needed to be boiled in hot water. Some of these herbs cost a thousand baht. However, nothing could help him walk again, so we stopped all traditional medicines and let he (a stroke survivor) exercise, walk, and take regular medications. He (a stroke survivor) strictly does them, and he finds that they help him get better. He can walk with a walker and ride his tricycle. (The ninth family)

However, most families did not have a clear understanding of the effects and side effects of the medications the survivors had taken for many years. They just memorized the types and appearances of the medicines. For example, they kept in mind that white tablets were to reduce blood pressure and to be taken after breakfast everyday. Stroke survivors had to take various medications in order to control several health problems such as hypertensive medications, anti-coagulant medications, anti-lypidemic medications, and brain cell stimulants. It is worth noting that some family members complained that they received very little information on the medications from the doctors due to a short visit. Frequently, the physicians told them, *"Take the same medications and come back for the follow-up next month."* Sometimes they had to learn about the medicines from the labels. Also, some hospitals wrote the names of the medications in English, which made it difficult for the family members to understand.

Moreover, all families provided care related to the stroke by taking the survivor to the doctor's follow-up on a regular basis. Many families accompanied their stroke survivors to see the physicians, especially in the first year of caring. After receiving long-term care, the survivors, particularly those who were not completely dependent, were taken to see the doctors at a healthcare setting. For these survivors, their families explained that even though the doctors prescribed the same medications and had no further treatment, accompanying their survivors to see the physicians allowed the survivors' health to be checked up (such as blood pressure or blood tests). The families also had a chance to share experiences with other caregivers who cared for disabled family members, and this made them learn. However, families pointed out the difficulties in moving and taking the survivors to see the doctors at the hospital. They also had to wait for so long and ended up not having time to discuss with the doctors. They said that they still wanted to get more information on the stroke, as well as its treatment and rehabilitation, although they had provided long-term care for their stroke survivors. For six completely dependant survivors, family members went to receive medications by themselves without bringing the survivors with them. According to them, it was difficult to move the survivors and the physicians also gave them the same prescriptions. The families would take the survivors to see the physicians only when they had complications such as having a fever.

Physical therapy or exercise was a caring task the family caregivers did for their survivors. All 14 families believed that exercise was a good way to help the survivors recover from physical disabilities. The third, fifth, sixth, ninth, and twelfth families encouraged stroke survivors to exercise regularly by themselves such as walking, doing activities of daily living, and riding a tricycle. Some survivors exercised by walking with double steel rails and using the weak arm to lifting weight. For stroke survivors who could not exercise by themselves, such as those in the forth, seventh, eighth, tenth, eleventh, and thirteenth families, family members helped them do that. They followed what physical therapists did to the survivors during hospitalization. These families said that they could not remember all they were taught but they performed only what they could do or what was less complicated, such as lifting arms and legs up and down, bending and stretching arms and legs, massaging muscles, and helping stroke survivors sit or be in a semi-fowler's position on the bed. The frequency of exercise activities depended on the free time of family members. For more well-to-do families, they paid a physiotherapist to help stroke survivors exercise at home. The fee was around 200-300 baht per hour. The frequency of hiring depended on stroke survivors' conditions and financial status of the families.

Turning to Take Care of the Family's Health

Providing long-term care for a family member at home made almost all families realized the significance of the health of non-stroke members. In particular, the health of family members who were primary caregivers would receive much attention as they tended to develop health problems as a result of their caregiving duties and aging. Other family members also took more care of their health due to the realization that they were important to their families as well.

The participating families said that they paid more attention to primary caregivers' health after having to care for their stroke survivors for many years. They described that at the beginning of caregiving, looking after the stroke survivor was their priority. After years of caregiving duties, they began to realize that the primary caregivers themselves began to develop health problems. Long-term caregiving often resulted in physiological and mental symptoms such as back pain, fatigue, and insomnia, as well as chronic stress. Consequently, families began to pay more attention to family caregivers' physiological and psychological well being. Some families stated that they were worried about what stroke survivors and the remaining family members would do if something happened to the primary caregivers. Therefore, primary caregivers were encouraged to have a health check-up and seek medical treatment to maintain good health, which in turn enabled them to continue their caregiving. For example, the fourth family expressed more concerned with the health of their primary caregiver. They not only encouraged her to have her back checked and to get treatment at the hospital regularly, but also sought for other alternative treatments recommended by others such as acupuncture and massage. They also bought milk high in calcium content for her to drink. Similarly, the primary caregiver of the second family seemed to develop long-term stress and physical health problems. Therefore, her family encouraged her to do activities that she loved or made her happy such as drinking in the evening. This family also gave her a painkiller ointment to relieve her muscle pain.

Likewise, the first family indicated that they originally paid less attention to the primary caregiver's health than to the stroke survivor's health because they thought that the survivor was a sick person. However, after one year of total caregiving including moving their stroke survivor, the primary caregiver began to suffer from back pain. Thus, the family took the primary caregiver to see the doctor and made her use a back support when carrying the stroke survivor. The ninth family also shared their experience of health problems that occurred to the primary caregiver after providing several years of caregiving. According to them, the survivor's caregiver developed multiple health problems with high blood pressure, stress, and insomnia, so she was regularly treated by the physician. In addition, her family tried to minimize stress and promote psychosocial well-being by temporarily releasing her from her caregiving duties, letting her stay away from the same caregiving environment, and enabling her to avoid a stressful situation, as they described:

> At present, I am more concerned with her health. Sometimes I say bad words to her, and I apologize. I think carefully before talking to my mom to avoid hurting her feelings. For example, I have changed my habits and now I come home earlier so that my father and mother will not have to worry about me and they can rest. When my father has a stroke, my mother was worried and could not sleep. Now, I pay more attention to her health because I am afraid she will get sick as well. More importantly, I am more concerned about her mental condition because she used to be overwhelmed with thoughts. She has taken care of my dad for a long time, and that is not good for her mental health. She had insufficient rest, too. (The ninth family)

Providing long-term care for stroke survivors made many families realize the importance of taking care of oneself. They had to pay more attention to their own health. Several of them were aware of long-term impacts of a stroke on the survivors' life. Consequently, almost all families intended not to make themselves fall victim to a chronic illness and become another disabled person in the family. As a result, they avoided risk factors of stroke. Furthermore, families realized that they were a vital supporting resource for their survivors and the whole families; taking care of themselves became one way they could take care of the families.

Many families witnessed that a stroke caused permanent sufferings to the survivors, so they expressed their fear of having a stroke in the future. For some families, they took care of their health with an aim to reduce the stroke's risks. For example, the eighth family believed that aging and improper eating habit caused their mother a stroke, so they changed their eating habit by eating less fatty and salty food, exercising more, and going to see a physician when they felt sick.

The second, third, ninth, eleventh, twelfth, and fourteenth families also felt that long-term caregiving made them afraid of the effects of stroke. They realized that a stroke permanently changed their loved ones to be dependent persons. They remarked that if they got a stroke in the future, it would be better to die than staying alive and becoming a burden for the family. These families paid more attention to their own health to prevent a stroke. Some said that after providing long-term care, they went to see the doctor whenever they got sick. Others had their health check-ups every year, particularly out of fear of high blood cholesterol which increased a chance of a stroke. Many families tried to control body weight, manage stress, and exercise. However, even though some knew the serious impacts of a stroke well, it was difficult for them to modify their risky life styles, as can be seen from an instance from the twelfth family:

> It has affected me because I see the example from my wife (a stroke survivor). It makes me so afraid. Hey, a stroke is very serious, and I have recognized its seriousness now. In the past, I knew only a stroke caused paralysis. After my loved one has had a stroke for nine years, I have to say that I do not want to get a stroke. Right now, I think if I have a stroke, it will be better to die than to live with long-term disabilities resulting from a stroke. I do not want to live in such conditions. I

> think dying from a heart attack would be less burdensome than living with a stroke. However, I cannot prevent it. I really cannot! I only try not to make myself tensed. … I must work everyday, and I always have a job to do. (The twelfth family)

Furthermore, for many families, providing long-term care for stroke survivors increased the sense of responsibility for the whole family. Stroke forced some family members to take charge of the whole family instead of the survivors. Consequently, they had to take care of their own health so as to be able to care for stroke survivors and the family as long as they could. Many families paid more attention to their health and adopted a better lifestyle for this purpose. For example, the tenth family tried to maintain their good health by exercising everyday and walking up and down the stairs regularly. They said that if they were sick or unhealthy, they could not take care of their survivor and would not be able to earn money to support the family. They noted that:

> Now, I am concerned with my health and my mom's, too. She always exercises by riding a bicycle for 30 minutes. She tells me that she has to be healthy to take long-term care of our survivor. For me, I always remind myself this while driving. I drive slower than 90 km. per hour and drive carefully to keep myself safe. … I become a key person of our family. I have to take care of my life for my family. (The tenth family)

This chapter describes the participating families' managements to provide care for stroke survivors at home for a long time. Families adjusted their home environment to be suitable for taking care of their disabled family members. They also learned to live with caregiving duties by adjusting the family's ways of living, managing stressful situations, dealing with family finances, and organizing family roles and functions. Moreover, prolonged care stimulated family members to pay more attention to other members' health, particularly primary caregivers' health as these caregivers tended to develop physical and psychological health problems as a result of long-term caregiving duties. In addition, many family members had increased self-awareness because they realized that they themselves were an important part of the whole family.

Discussion

Family management in long-term care of stroke survivors at home was relevant to family system perspectives, which revealed an interaction among subsystems in the entire family to make the family life continue and to learn to live with changes resulting from long-term impacts of stroke. Every family experienced adjustment of their home environment, learned to live with caregiving for the survivors at home, and took care of the family's health.

Part 1: Adapting the Home Environment

The study findings showed that home was perceived as the best place of care for stroke survivors. None of the participating families had an idea to abandon their long-term caring responsibilities by sending stroke survivors to be cared for in other places. This result is different from research findings conducted in Western countries, which mostly indicated that Western families preferred to send long-time survivors from chronic diseases to long-term care facilities. For example, Munter, Garrett, Elay, and Coresh (2002) conducted a study on stroke patients who were discharged from the hospital and found that from 1981 to1994, stroke patients were increasingly sent to long-term care facilities, with the percentages increasing from 6.3 percent to 8.9 percent. Besides, such studies reflected the burden the families of long-term stroke survivors placed on social and healthcare systems. The findings of the present study are different from the phenomenon of caring for long-term stroke survivors in the western world because for caring for an ill family member at home by the family is one of the Thai family cultures. Therefore, it can be concluded that the Thai family system is an important source of long-term care for long-term stroke survivors.

Besides, participating families modified the house to be a long-term care setting for their stroke survivors. Medical appliances and other necessary equipment were installed for the survivors and this became a common practice for every family providing long-term care for the survivors at home. This finding yields support to the findings of Palmer and Glass (2003) and Pound, Gompertz, and Ebrahim (1999) that for families living with stroke survivors at home, they adjusted their homes, especially the bedrooms and bathrooms.

Part 2: Learning to Live With Caring for the Survivors at Home

The notion that "the survivor is the center of the family" influenced families to learn to arrange daily living activities in many directions including patterns of sleep and rest, participating in social activities, working, and re-planning their family plan in the future according to permanent disabilities of stroke survivors. Likewise, the findings of the study carried out by Oranee Kapchai (2002) suggested that members in the Thai family system in Chiang Mai were involved in taking care of each other based on the feelings of love, concern, and deep emotional relationships. Also, Junda (2002) found that Thai families caring for female patients with breast cancer adjusted their ways of life to care for and live with their chronically ill family members. Furthermore, Finkelman (2000) pointed out that caring for a mentally sick member for a long time made the families adapt their previous plans in life. These results could be explained by the system perspectives that families learn how to interrelate with one another to live together rather than learning to live individually (Friedman, Bowen and Jones, 2003, p. 153).

All 14 participating families in this study were Buddhists. The results showed that families' ways of living, including coping with emotions and stress, was influenced by the religion's principles. It could be explained that because the family is an open system, multiple factors within and around the family influence the ways of family life. It means that Buddhism has an influence on Thai families regarding how the families perceive the situation, behave, and manage their life. The participating families perceived that caring for a dependent family member was a suffering, which caused the family's stress. Therefore, they tried to minimize additional stress in their family.

In addition, successful conflict management in their family life reflected the ability of Thai families to cope with a crisis, as Stinnett (1983, as cited in Yodpetch, 1996, p. 206) pointed out:

> *To have the ability to effectively manage a crisis in the family is a good prevention of problems. The qualified families have good methods of problem solving to overcome that crisis to maintain usual family life. Although facing with problems or sufferings seem to be natural for human beings, qualified families can manage the difficulty smoothly. Cooperatively fight the problems instead of being discouraged or separated can encourage the families to deal with the problems successfully.*

The findings derived from this research also indicated that families dealt with family finances through assistance and support they had for one another. One plausible explanation is that despite the mist of social and structural changes that have made the size of the families in Chiang Mai smaller, the Thai family norms and traditions still endure. Families realize their roles and responsibilities in providing assistances for family members. Moreover, family members also depend upon one another for financial and social supports in various forms based on an understanding of each other. Thus, the Thai family system has been a major source of support for the people (Poowongprate, 1997).

As regards altered roles and functions in participating families as a result of long-term care of stroke survivors, the study findings showed that family members utilized role transfer or role replacement, particularly the roles previously played by stroke survivors. Similar findings were found in the study of Smith et al. (2004) that alterations in roles and functions were a major issue in the family caring for long-term stroke survivors, with the alterations involving a reversal of domestic male or female roles, which posed additional responsibilities, and a transformation of roles among family members. In this study, due to stroke survivors' inability to fulfill personal roles and functions, their previous roles were transferred to other members. On top of this, family members had to share the roles of caregivers and housekeepers. The strategies employed by the families also reflected self-supporting characteristics of the Thai family. Many families said that, "we cannot depend on other people, and we have to depend on ourselves or our family first." This finding was in congruence with findings of previous studies. For instance, a research study on healthcare activities of the Northern Thai people by Benja Yoddumnearn-Attik, Junya Setthabuppha, and Krittaya Archawanijjakul (1982) revealed that people in the North mostly initially depended on themselves. This could be explained by examining the effects of Buddhism on the Thai people who are taught by the religious teaching that, "one must endure and one must depend on oneself" (Limanon, 1995).

It is noticeable that many families organized their roles and functions by transferring the role of the family head to female family members such as the wife or the daughter. This situation is relevant to the characteristics of families in the North, which are different from those living in other parts of Thailand. The family system in the North is a martrifocal system in which the family is run by women (Caffrey, 1992).

Part 3: Taking Care of the Family's Health

The healthcare function is an essential and basic family function (Friedman et al., 2003, p. 434). The research findings demonstrated that families provided care for the whole family's health including stroke survivors and the other members. The findings confirm the Thai family value, which pays attention to the entire family's health and mutual values. Even though a family member was permanently dependent, the family is willing to take care of his/her health in order to sustain him/her. It can be explained by system perspectives that a family is an interactive system, with healthcare belonging to the whole rather than a part. Furthermore, the study findings also highlighted the characteristics of the Thai family, which has family members' health as a basic function of the family.

Some caring strategies shed light on the influences of traditional beliefs on caregiving behaviors. Due to the belief of "bad foods," which were not good for health, some families avoided preparing these foods. Beef and bamboo shoots were mostly mentioned because they believed that these bad foods caused the survivors to faint, itch, or even die. Some families believed on "cold foods" that should not be eaten by stroke survivors, particularly roots such as bean sprout, potato, and white carrot, which were believed to cause spasm of paralyzed muscles. Such beliefs were formed based on words of mouth or learned from experiences of other sick patients with the same conditions. The belief reflected the influence of external environment surrounding the families on healthcare behaviors according to the characteristics of an open system of a family (Friedman, Bowen & Jones, 2003, p. 155). Culture also affects families' belief because "bad foods and hot-cold foods affect health" is one of the traditional beliefs in the Lanna community, which have been transferred from one generation to the next (Anan Kanchanaphan & Chaladchai Ramitanon, 1994; Norujorn Ittitherajarus, 1988). Although this belief is difficult to explain with scientific reasons, the families provided long-term care for stroke survivors followed it. This finding is consistent with the findings of a study conducted by Achara Sukontasub et al. (2002) which explored the arrangement of daily life of paraplegic Thais and a study of Nilmanat and Street (2004) investigating the families caring for HIV/AIDS patients in the South of Thailand. The research results indicated that healthcare behaviors were formed based on the concept of bad foods.

Participating families responded to caring activities and caring problems by seeking knowledge and information. All families experienced seeking for other forms of treatment in the first year of caring in hope that they would help the survivors recover. Such practice is often demonstrated among families with chronically or critically ill members in Thai and Asian cultures (Friedman, Bowen & Jones, 2003, p. 573). However, no family mentioned alternative treatments with supernatural powers. This reflected external factors such as socio-culture in a modern society, improvement in education, and scientific knowledge development of Thai families (Narujorn Ittiteerajarus, 1988). When caregiving became long-term and alternative treatments could not cure the survivors, families stopped searching for alternative treatments. They continued care with modern medicines, including medication and physical therapy. Seeking knowledge and information also helped the families better understand about stroke whose symptoms could be alleviated with these modern medicines. The finding is similar to the finding of Achara Sukontasub et al. (2002) which suggested that Thai families caring for paraplegic members often sought alternative treatments, particularly in the first two years of care.

Many families experienced problems during caring for their survivors. Difficulty in taking stroke survivors to hospitals and constipation were significant problems mentioned by all families. Families learned to solve these problems through (1) trials and errors, (2) other persons who had the same experience, (3) their own previous experiences, (4) self-study, and (5) consultation with healthcare providers. Gaining knowledge and useful information increased the families' sense of control over the situation, reduced their fear of problems they experienced, and also modified their caring tasks.

Data derived from this study also revealed that there were only three families that continued to receive homecare while giving long-term care to stroke survivors. The other five families had homecare services in the first three to six months of caring for stroke survivors at home. For the three families receiving continuous homecare, they were satisfied with the service and recognized its usefulness. The other 11 families mentioned their need for homecare or any long-term care at home. The research findings shed light on insufficient health services including information, on-going care, and preparation of families caring for a member with a chronic condition at home. This finding is consistent with that of a study conducted by Wilkinson et al. (1997) which concluded that long-term homecare service for long-term stroke survivors was the most necessary, but in the real-life situation this services was not enough, as one-third of the five-year stroke survivors were physically deformed and had limitation in their ability to perform daily and social activities. Therefore, to improve the survivors' ability in self-care and the family members' ability to provide care, homecare services should not end after the first period of stroke. Similarly, Smith et al. (2004) also reported that caregivers of a stroke survivor found that they received little contact from healthcare providers (i.e. physicians, nurses, or therapists), lacked follow-ups, and lacked continuity of home help services, which meant that they had to learn to provide care by themselves. The findings confirmed the need for homecare for families providing long-term care for stroke survivors at home.

Long-term care for stroke survivors at home caused the families turn to pay more attention to the health of other members in the families. The two main reasons were (1) physical health problems occurred to primary caregivers as a result of caregiving duties, and (2) they were concerned with the health of other family members who they realized were also an important part of the whole family. Proving long-term care for the survivors combined with aging caused health problems or somatic symptoms to participating primary caregivers, which often manifested in the form of muscle pain including backache, knee ache, back pain, as well as high blood pressure. The primary caregivers' ages in this study ranged from 39 to 67 years. Of these, ten were older than 50 years old. Additionally, all caregivers had played the new role since the survivors were discharged and returned home. According to Han and Haley (1999) and Palmer and Glass (2003), a family member who takes the role of a primary caregiver becomes a risk group of health problems rather than other family members because of playing the new roles and doing the new functions. Moreover, a stroke is a chronic disease which causes long-term physical impairments to long-term stroke survivors, so primary caregivers become a long-term important resource for them. Caring for a stroke survivor for a long time requires dedication of family members, in terms of time, physical power, and mental power, particularly when the survivors need much more care due to the level of disabilities. This result is similar to the results of other studies on caregivers of stroke survivors, confirming that these primary caregivers had emotional tension and stress resulting from taking care of stroke survivors for a long time (Anderson et al., 1995). Moreover, a study of Grant, Weaver, Elliott, Bartolucci, and Giper (2004) indicated that the primary caregivers who had health problems from caring for stroke survivors were at a high risk for depression. In addition, family members, especially aging primary caregivers, are often stricken with physical deterioration and health problems such as ache, pain, weight loss, easily tired, and exhausted (Natechang, 2002; Teel et al., 2001).

Many stroke survivors' caregivers said that they paid attention to caring for stroke survivors and forgot to take care of themselves until unusual symptoms occurred, which made them, as well as other family members, begin to pay more attention to their health. Saipin Kasemkitwattana (1993) has contended that primary caregivers caring for chronically ill patients spent most of their time, especially in the first period of caring, on performing caring activities and lacking time or paying less attention in caring for their health until they detected the symptoms of deteriorating health.

Besides, becoming primary caregivers made family members plan for a long-term caregiving duty for the survivors and encourage other members in the family to recognize their significance to the family life on a whole. Other members turned to pay more attention to and be more concerned with their health to save their life for their family. This family experience portrayed the value of the Thai family system in Chiang Mai that had not yet become a fully individualistic culture. Instead, the family system retained the deep connection and responsibilities among family members. Moreover, this finding also highlighted the strength of Asian families, including Thai, which is referred to as famalilism, with recognition of the whole family, family kinships, and mutual responsibilities. This particular characteristic is significantly different from the characteristic of a Western family system (Friedman, Bowen & Jones, 2003, p. 568).