CHAPTER 5

FAMILY LIFE CHANGES AFTER HAVING A PERMANENTLY DISABLED FAMILY MEMBER

This chapter provides thick descriptions of the family experience on changes from having a permanently disabled family member, and the descriptions are divided into two parts: encountering having a disabled family member and changes in family life. In the first part, data reflect the entire family facing with an unexpected stroke attack, the stroke survivor's psychological changes, and acceptance of having a disabled family member. The whole family's life also changed as a result of providing care to a family member with chronic disabilities including increased family expenses, decreased family income, decreased family social activities, altered family roles and functions, increased family responsibilities of being caregivers, and also increased family cohesion.

Part 1: Encountering Having a Disabled Family Member

The occurrence of a stroke was a shocking and unexpected experience for all families. It happened suddenly and caused the whole family distress as they confronted a threatening condition. A stroke changed the survivor from having to deal with a frightening life event to surviving. The family member who had survived a stroke became a disabled person with functional disabilities who needed to be cared for by their family. The survivors also had to deal with their psychological changes such as loss of confidence, fear of death and being abandoned, and inability to cope with long-term physical disabilities. However, participating families expressed that providing long-term care helped them to become familiar with the survivors' condition and therefore to finally accept the functional limitations of the stroke survivors.

Facing With Unexpected Stroke Attack

A stroke was a life threatening condition as perceived by all families because of its sudden and unexpected nature. As a result of this event, a survivor's life was changed to that of a disabled person who needed care from his/her family. Participating families expressed that a stroke "shocked" their families, because it was a sudden change that they never expected would happen to their family. All families said that they feared losing their loved ones from a stroke.

The twelfth family, for instance, described their experience that they never thought that a stroke would happen to their family because the survivor used to be a healthy woman and always played many kinds of sports. Thus, when a stroke occurred and the survivor was in a critical health state, they were shocked with this situation as a family member said:

> …She (a stroke survivor) was admitted to the I.C.U. at … (a hospital's name). The doctor often told me that my wife's condition was so critical that she could die in any second. That really scared me. At that time, I felt like I was encountering death, which could claim the life of my wife in a split second. (The twelfth family)

Likewise, other families shared their experience of facing an unexpected stroke attack, which let them encounter losing their loved one and think that it was the survivor's end of life:

> When my wife was in I.C.U., I thought that she was in a coma and she would die any time. So, I consulted with my children and relatives that if she died, we would take her to Chiang Rai. I was sobbing as I spoke. … (The thirteenth family)

> I felt horrible. I thought I lost my dad when he was admitted to the hospital. He was unconscious. I thought surely he would die at that time. (The ninth family)

After surviving, most of the families initially could not accept that their loved one became a deformed person, and also, due to a lack of knowledge about the disease, wished that their disabled family member would recover and return to be a normal person. They only expected that stroke survivors had to be cured. Moreover, the families were still afraid of being faced with unexpected health conditions or another stroke even after they had been caring for stroke survivors for years:

> At that time, he lived, and then we thought just that he (a stroke survivor) would eventually be able to walk, work and speak, as he had been… (The ninth family)

> … We'd never known this disease (a stroke) until it happened to my husband (a stroke survivor). He said that he would recover and get back to normal. We hoped so because our neighbor who was also a stroke survivor told us that a few months after his stroke he was able to walk, eat, and speak. This neighbor walked to visit my husband at home, just like a normal person. (The third family)

> … For me, it is unbelievable that she (a stroke survivor) is now a disabled person, who cannot drive, play tennis, and cook as she used to… During nine years (of caring for a mom with a stroke), there was a period when her disease recurred and she had to be hospitalized many times. I was afraid every time she was admitted to the hospital. I feared she'd die. (The twelfth family)

Facing With Psychological Changes of Stroke Survivors

In addition to becoming a person with physical disabilities, several families stated that a stroke had decreased the survivors' self-confidence to do activities by themselves. They also expressed the survivors' fear of death and being abandoned. Furthermore, the survivor could not accept their current physical disabilities. They still had an expectation that they would be able to fully recover and be a normal person again.

Family members reported that before getting a stroke, stroke survivors had been confident in doing everything and had no fear of anything. However, when they became a permanently disabled person, their self-confidence decreased, and that made them unable to do activities, particularly walking alone. For example, a two-year stroke survivor of the eighth family did not ever try to walk alone because of the fear of falling down. Consistently, when the researcher visited this family and asked the survivor to practice walking with a bamboo-made grab bar or stand up with her walker, she had to call her daughter or husband to be with her. Her daughter told me that the mother used to be confident in doing everything by herself, but after being a stroke survivor, she lost her self-confidence and did not dare to do any activity on her own. Similarly, the second family shared this experience that their stroke survivor lost his confidence to do activities by himself:

> In the past, he (a stroke survivor) had very high self-confidence. He did everything as he wanted and went everywhere alone. After getting a stroke and being a disabled person, his confidence is lost. We often encourage him to get up from the bed and walk. He refused. We think that he lost his self-confidence to walk because of the paralysis on his right side of the body. (The second family)

Some stroke survivors were also afraid of staying home for a long period of time due to fear of death and being abandoned. Participating families, such as the second, the third, the eighth, and the twelfth families, indicated that their stroke survivors needed someone to stay with or nearby them. For example, the researcher visited the third family when the stroke survivor's wife went out for vending, and this survivor said that his wife would get home on time, around 11 o'clock in the morning. When the time was near 11 o'clock, the survivor got nervous and moved his wheelchair to the front door to get a clearer view of his wife. A family member mentioned that the survivor would be very annoyed and angry if his wife came home late. According to this family member, he often said that she would abandon him one day because of his disability:

> My dad (a stroke survivor) doesn't want my mom to go outside. She always tells me she wants to go here and there, but I'd tell her to ask my dad for permission. If he says 'yes,' my mom can go, but he'd ask where and how she is going to go there and when she would be back at home. If it's time but my mom doesn't get home yet, my dad would become furious. He often says that we will abandon him and let him stay home alone. One day my mom went to sell foods and came home late, she was questioned why she went out for a long time, why she left him alone, and what he would do if something wrong happened to him. (The third family)

The twelfth family also shared the same experience. The husband and his son reflected the changes in the stroke survivor's psychological state after having suffered from a stroke for nine years. According to them, she was volatile and frightened of being abandoned and dead. She kept repeating with the family members that if something wrong happened, she could not help herself:

> My wife (a stroke survivor) is afraid of death and fire. Once a house nearby was on fire, she was afraid that she couldn't escape and would die in the fire. She doesn't want to die. She's fearful of being abandoned and having to live alone. (The twelfth family)

Besides, several families perceived that stroke survivors were unable to accept their current physical disabilities even though they got a long-term stroke, as evidenced by an account from the ninth family:

> …When my dad had a stroke, he was hurt so much that he wanted to kill himself. He felt very hurt for not being able to go anywhere, do anything, and for having to depend on others. … He thought of committing a suicide. He actually tried it!, but it was very lucky that my mom happened to see him while he was trying to hang himself. That was around five years after he had a stroke. He seemed bored of himself as he thought he'd suffered this disease for too long and kept asking why he still hasn't had a full recovery after receiving various methods of treatment. … He cried and said he didn't want to live with his disabilities any longer. (The ninth family)

Likewise, a stroke survivor of the twelfth family used to be a healthy woman, but nine years of being a stroke survivor changed her to be a disabled person who could not walk and perform daily activities. Her family stated that although the stroke survivor had for a long time suffered from the stroke, she could not accept the truth that she was a disabled, as one of the family member reported:

> Until now, she can't accept the fact that she is sick. Once our relatives came to visit her and told her to try to move from here to there by herself, she then tried to sit on the floor and used her hands to move her body forward. She said that she tried to move by herself and told us not to help her. She said she is not disabled and not a patient. She misunderstands that that it's just a short-term disease (a stroke) and that she can recover and get back to her old self. (The twelfth family)

The third family also found that their three-year stroke survivor was unable to accept that he had physical disabilities with right-side paralysis. He still had an expectation that he would be back to play the Thai musical instrument and write proverbs as he used to:

> He often says that his right hand and leg are temporarily disabled. When he felt pain on that side, he said he would be back to normal very soon because of feeling pain. He hopes that he will be better in the third year, can use his right hand to play a fiddle, and to write again. (The third family)

Acceptance of Having a Disabled Member as a Part of Family Life

However, taking care of the survivors for many years allowed the family to become used to the survivors' conditions, as well as the situations around them. They also had time to think about these changes. They realized that it was difficult for the survivors to be the same person as they were before the stroke. In addition, after several years had passed by, these families gained more understanding about a stroke, a disease causing a disorder in the brain, from which the patient cannot fully recover. Finally, all the family sympathized with the patients and could accept that they had a member with permanent functional disabilities who had to depend on others and/or necessary equipment such as wheelchairs and canes. They eventually accepted that this situation was the family's karma.

The ninth family, for example, explained that caregiving of a stroke survivor for more than a year allowed the family to familiarize themselves with the survivors' condition they had seen and lived with for many years:

> Initially, I couldn't accept that my father had a stroke. … I've seen him in that state for such a long time and my hope for seeing him fully recovered has been dashed. Everyday, he goes to bed early and during the day he has a meal in the afternoon

> and then sleeps and wakes up around 2 o'clock in the afternoon. It seems like I accept his state at present. (The ninth family)

Similarly, the twelfth family accepted that the survivor's condition became a routine they had seen for nine years, as a family member described:

> Time heals all wounds. I think I got used to it when time went by. It's normal that we were shocked by the sudden changes but now we have gotten used to it. My family began to accept her condition. We've seen it for such a long time that we began to accept that it isn't unusual. It's not strange now, as time has allowed us to get over it. It's something like a graph that the curve is gradually going down. We have calmed down and don't feel that it's a big problem. … (The twelfth family)

Some families indicated that the long-term care provided for a stroke survivor at home made them understand what the stroke was. This understanding supported them in recognizing that the survivor's health condition would not return to normal:

> At that time (when a stroke occurred), I did not know about a stroke. After she fell down many times, we took her to be checked. The physician said she got a stroke. What was a stroke? Then, her condition got worse that we though she would die. After a two-year survival, she became like this. We asked a physician about its cause. He said a stroke is a disease of our brain, which suddenly loses blood supply. It causes the patient physical dysfunction. It is not a fatal illness that can kill her immediately. We cannot do more for her condition because her brain is damaged and it is about defected brain cells. So, it is acceptable. I really know that my wife's health (a stroke survivor) is in this condition. (The thirteen family)

> … The other thing that made me accept her disabilities is I know more about the disease now. I understand that it is a disease of the brain, not like an infectious disease, which can be cured with antibiotics. It's different! So, when we know that, and we also know she will be in this condition for a long time. (The twelfth family)

Furthermore, all 14 families stated that "time" allowed them to learn to accept the truth of what had happened to the survivors and their families. They turned to Buddhism to help them accept that it was the family's fate, or karma, to have an impaired family member. They thought only that this situation was unavoidable and it was impossible to anticipate any change:

> … I kept wondering why it turned out like this. But when I entered the monkhood, I felt like I was enlightened to understand that whatever will be, will be. … I often told my mom to keep thinking that it was his (a stroke survivor) karma in the past life. Caring for him is not only our family's worldly responsibility, but it is our karma that we have together. (The ninth family)

> …Now, I just think he (a stroke survivor) suffers from a stroke, cannot walk or do whatever he had done before, because of his karma. He was a person of bad behaviors, and now he is living with his consequences. On the other hand, we live in the same family, so we should bear some part of these consequences together and for a long time. It's our karma, too. (The fifth family)

> … Nothing could harm us any more. If she died we would not cry, or be unhappy, but we will be happy that she paid back for her karma. Now, we think that she is being a disabled person because of her karma. (The tenth family)

Additionally, accepting that the survivor had become a person with permanent functional disabilities enabled the family to have positive feelings towards the survivors. The family members stated that their feelings of love, compassion, and sympathy actually increased. Bad behaviors of the survivors in the past and other improper expressions such as anger, irritability, demanding nature, and/or alcoholism were forgotten and replaced by these positive feelings and the feeling of "being in their shoes." Participating families explained that they sympathized with and forgave the survivors because they realized that the survivors suffered from a stroke, would never recover and return to their old self before the stroke, and had to live with their physical disabilities for the rest of their life, as some expressed:

> … Our relationships, feelings, and bonding with her (a stroke survivor) remain the same even though she's often furious at us. Instead, we have compassion for her. We didn't feel like this towards her when she was healthy. We take pity on her for being a stroke victim. (The twelfth family)

> We don't think about how badly he behaved before because now he is facing great sufferings. He cannot live a normal life—walking, drinking alcohol, and so on. … All of us sympathize and forgive him, and his daughter, too. … (The fifth family)

> I feel more love for my grandma and I feel much sympathy for her when seeing her suffering from a stroke. She can't help herself. It's torture, and she is probably under a lot of stress. (The eleventh family)

Part 2: Changes in Family Life

As a result of caring for a person with chronic disability in the family, as well as stroke survivors' wants and needs, the participating families experienced many changes in their lives, particularly the entire family' financial status, which was affected as the family now had more expenses, and often with decreased income. The family's social activities also decreased. Moreover, roles and functions in the family were altered. Increased responsibilities of being caregivers changed the family's structure as well. However, family cohesion improved as perceived by almost all families.

Increased Family Expenses From Providing Long-Term Care

When a stroke occurred, all stroke survivors required hospitalization for diagnosis, treatment, and care by professional healthcare providers. Many families addressed that the medical expenses for hospitalized stroke patients were very high. Furthermore, after being discharged after a long period of hospitalization, families still took responsibilities for caring for stroke survivors, particularly for some necessary equipment including diapers, plastic sheets, and instant diets. As a result, families' expenses had been increased since a stroke occurred.

Family expenses at the onset of the stroke were vividly imprinted in the memory of many families as they had to cover both direct costs and indirect costs. Direct costs included diagnostic procedures, medications, and hospitalization, which depended on stroke survivors' severity of the illness. Indirect costs were transportation costs, loss of work, and costs for additional treatments. Several survivors were in a coma and they were unconscious and required a long period of hospitalization. Increased expenses had become a burden on the family as told by several family members:

> Initially, the costs were quite high for medicines, equipment, and treatment costs. All of the money we had were used to pay for them. I spent all of my savings at that time. (The sixth family)

> …My wife stayed at the hospital for almost a month and I spent nearly 400,000 baht for the treatment cost. It was quite expensive. Approximately 400,000 baht for staying at the hospital for less than a month was a very large sum of money. Around a month later, she needed someone to watch her. I hired a paid caregiver to take care of her. Later on, we sent her to …(a name of a private clinic) and it costs around 20,000 baht a month. … (The twelfth family)

> My father was in quite a bad condition and had to be in the ICU. At that time I had to work hard and do overtime work in order to make money for the treatment cost. It was very expensive, but we had to pay it. Every day he was hospitalized, we had to pay for medications, the CT scan, X-ray, diapers, diets, and so on. My mom went to visit him and stayed with him until late evening everyday. We spent a lot. (The third family)

When a stroke patient returned home, the changes following a stroke impacted the survivor on their ability to perform daily activities. The home environment itself affected the patients' performance. Families had to prepare home environment, equipment, and necessities for looking after stroke survivors at home to ensure their well being and their safety, which depended on the survivor's health status. Consequently, after discharge, families continued their payment for the survivors. All family stated they were given some advice from healthcare staffs at the hospital on preparing equipment and facilities for the survivors such as beds, airbeds, and wheelchairs. Some equipment could be prepared because of the observation of family members at the hospital. For example, the seventh and eleventh families whose bedridden survivors retained tracheostomy tube bought a suction machine and a home oxygen therapy. The eighth family prepared a wheelchair for bathing, and the seventh family bought equipment for preparing blenderized diet. The first family built a new bedroom and installed necessary materials for the survivor. Certainly, all of these were a family cost, as some shared this experience:

> Before my mom returned home, a head nurse told me to buy a bed like a hospital bed, or an alpha bed to prevent bed sore wounds, and other equipment needed for taking care of her (a stroke survivor) at home. A hospital bed was cheaper than an alpha bed. I also modified a bedroom just for her. You see, there is no step at the room's doorsill for a wheelchair use, and we have installed a side rail in the bathroom. … I paid a lot for preparing them before taking her back home, around 100,000 baht. (The first family)

> She (a stroke survivor) could not breathe and cough normally. So, she came back home with the tracheostomy tube, which needed suction. Sometimes we saw nurses administrate her oxygen before and after suction. We prepared a tang of home oxygen and a suction machine at home. Those were only some parts we prepared and spent on. (The eleventh family)

> We built a new bedroom with a toilet for him (a stroke survivor) because he could not go upstairs and walk so far. We bought a commode, a urinal, a wheelchair, and a cane. They were expensive. So, the things that were considered to be more important, we bought them first. We spent a lot of money for him. (The second family)

Regarding providing long-term care, all families reported that they also had to take responsibility for expenses related to medications, treatment-related costs, and equipment for a long time. Among participating families, many families mentioned that they had to accept long-term spending for equipment including plastic sheets, diapers, and instant blenderized diets which could not be reimbursed. All these three things were mostly used by stroke survivors who had less ability or inability to help themselves and/or had bowel problems. It was found that six families used both diapers and plastic sheets. Among seven stroke survivors who could not take oral feeding, five of them were fed with instant food while the other two were fed with fresh blenderized diets. Some family members commented:

> … She (a stroke survivor) uses many pieces of diapers each day and two cans of Pan Enteral per week. They are quite expensive, but we have to pay for them. Two years after she has got a stroke, we spend about 10,000 baht per month. … (The tenth family)

> We have spent money on diapers and plastic sheets every month for many years. These are expensive but necessary for him (a stroke survivor). So, we have to be responsible for these costs for a long-time. … (The seventh family)

Meanwhile, the twelfth family also agreed that their family expenses increased because they were responsible for long-term care for a stroke survivor, which required high expenditure:

> I used to calculate how much I pay every month for hiring a caretaker to take care of her (a stroke survivor), including the electricity bills which are around 6-7,000 baht every month because the air-conditioner is turned on all day long. As for food, she prefers only expensive foods and fruits. All of these costs are quite high. I also have to pay for the caretaker's wages and her foods. Our family's expenses are higher as we hire a worker to help take care of her. (The twelfth family)

Decreased Family Income

Long-term survival from a stroke meant the survivors were unable to return to work, and this could cause problems, particularly for families where the stroke survivors used to be the principle family income providers. Therefore, families faced decreased family incomes, especially those that used to come from the stroke survivors.

None of the stroke survivors could resume their work to earn their living for the family. Even though some of them showed physical and cognitive recovery, their conditions did not allow them to do their previous works such as a Thai musical instrument teacher, a furniture and home decoration maker, a musician, and a farmer. For those who were unconscious or had complete dependence such as the fourth, the seventh, and the tenth families, they absolutely did not have a chance to go back to work. Therefore, they could not earn income for their family because of inability to work:

> He used to repair bicycles, motorcycles, and so on. His job earned him money every day, which was enough for our living. He also taught many children to play Thai musical instruments every evening because he was good at playing many kinds of Thai musical instruments. We also got money from his extra jobs. In the past, even though our family was not a rich family, we never faced financial difficulty because he was able to work and make money every day. But, currently, his right side is paralyzed. He cannot go back to work as he once did. Our family lacked income since he got a stroke. (The third family)

> She (a stroke survivor) was responsible for our family. She worked as a government employee at … (a name of the survivor's office). She got around 20,000 baht per month. Some months she earned more because she did overtime work. It was enough for our family's living. Now, it's different. Absolutely

> different! Her condition doesn't allow her to go back to work again. So, we will never get income from her, forever. (The tenth family)

Taking care of a stroke survivor required expenses since the onset of the stroke. Families faced an increase in family expenses due to prolonged responsibility for expenditures related to care of the survivors. In addition, in the families where the survivors used to be the breadwinners, they had to live with a lower amount of income as a result of the stroke survivors' inability to work.

Decreased Family Social Activities

All family perceived that prolonged care for a disabled person at home restricted their social life. Activities that were once taken for granted were now awkward and difficult to accomplish. They stated that initially they had automatically reduced and very limited opportunities to participate in outdoor activities together such as traveling, going to make merits at a temple, and joining social activities due to the caregiving activities. After providing care to the patients for a year, the feelings of concern for the survivors and the difficulty of the survivors' movement were major reasons that forced family members to refrain from taking part in social activities.

Families stated that initially the fact that stroke survivors were cared for at home diminished opportunities of families to do activities outside home together. One family member explained:

> During the first year of caring for my mom, we couldn't attend any meeting or go shopping due to many duties of taking care of her because of her completely dependent condition. These duties were new to us and we had to think about them rather than arranging time for our outdoor activities. (The first family)

As for the ninth family, they had to take care of all daily activities of a completely dependent stroke survivor during the first year at home. Therefore, it was impossible for this family to participate in activities outside home such as visiting their relatives in other provinces, going sightseeing, or joining their neighbors in some community's festivals:

> We could not go anywhere because he could not do anything after being discharged from the hospital. We had to take care of all of his daily life activities, from the early morning to late evening, until we took him to bed. Don't even think about going outside even it was in our community. It was impossible just to think about it. … (The ninth family)

Taking care for a long time, several families reported that although they had settled care activities into a routine, their stroke survivors still had movement difficulty, which limited outdoor activities of the whole family. A four-year stroke survivor of the fourth family, for example, was unable to keep his balance or help himself. Thus, it was tough and difficult for his family to take the survivor out of the house to make merits at a temple or visit tourist destinations. The family said that they often joined religious activities together at the temples in Chiang Mai and nearby provinces. These activities were stopped because of the survivor's health condition. The survivor's wife showed the researcher many pictures which were taken while the survivor was still healthy. These pictures depicted the family members and the stroke survivor doing outside activities on different occasions. This family also said that their family was unable to participate in these activities any longer as long as the survivor was still alive. Similarly, other families also shared the same sentiments as they stated:

> … When my wife was still healthy, we, three of us, drove to visit relatives in Lampoon. Sometimes we spent a night somewhere else. But now, these activities are stopped because she cannot sit for a long time. … (The thirteenth family)

> Every weekend we didn't stay home. We drove to temples, to our garden, and wherever we wanted to go to. But, since he got sick, he couldn't drive a car and I had to take care of him at home. So, most of our life is spent inside this house. (The fourteenth family)

Moreover, functional disabilities became the other reason that limited this family from performing outdoor activities together because of inconvenience of transportation and accommodation. It was difficult to move the stroke survivor as he had paralysis and needed some kinds of medical appliances. Families explained that for such a reason, it was a hardship to take the stroke survivor outdoors with the family. The second family, for example, said that they once took the survivor to Chiang Rai after two years with stroke. They faced the survivor's inconvenience for toilets and discomfort during traveling. As a result, this family hardly went anywhere all together or made a long trip now:

> We always visited our relatives who lived in Chiang Rai every New Year's day. We often went to make merits at temples in other provinces. Two years ago, we took him (a stroke survivor) to Chiang Rai. When we were there, it was very inconvenient for my dad when he needed to use a toilet. He also complained that he felt pain at his buttocks while we were on the way to Chiang Rai. So, it seemed our outdoor activities are ceased because of his movement and walking difficulty. (The second family)

Similar sentiment was found with the fourteenth family, whose stroke survivor's slow and difficult movement caused a driver of a hired red truck complained and was impatient to accommodate the stroke survivor and his disability. A family member recalled:

> I could get him (a stroke survivor) outside on a red truck but he walked very slowly. The driver could not wait so long and asked why he was so slow. So, it is not possible for us to perform outdoor activities. (The fourteenth family)

The sixth family also shared the same experience as follows:

> Even though he (a stroke survivor) has recovered, he is still not a normal person. Because of his movement difficulty, it is quite difficult for us to take him outdoors by public transportation. It is inconvenient, I think, so, we decide not to take any trip or go outside, except taking him to the hospital. (The sixth family)

Some families mentioned that they could not join outdoor activities or take a long trip together without the survivors because they were still unsure that it was okay to let the survivor stay home alone and were worried about the survivors' safety and well being such as concern about falls and meal preparation. As a consequence, outdoor activities of the whole family were much less frequent:

> My mom worries a lot, even if she goes out for only half an hour. I do, too, and we cannot go anywhere, because of the worry about what might happen to my sister (a stroke survivor). (The tenth family)

> We are very concerned about her (a stroke survivor) that if we go outside while she (a stroke survivor) is at home alone unexpected things may happen. My husband

> and I used to go to meetings and parties frequently, but now, it's different because if I go, I'm very worried about her (a stroke survivor). (The eight family)

Long-term caregiving provided for the survivors at home limited the chance of the families to do outdoor activities together because of difficulty in movement of the survivors and feeling of concern. Moreover, taking care of the survivors changed roles and functions in the family.

Alteration in Family Roles and Functions

When a family member got a stroke and became permanently disabled, roles and functions in the family differed, as a stroke survivor was unable to complete his/her roles and required someone to become his/her caregiver. Consequently, certain members in the family had to perform the roles of a caregiver as well as the survivor's previous roles.

Functional disabilities of stroke survivors caused them to have someone to take care of their life. Roles of the primary caregivers of stroke survivors were considered to be an extra role which was clearly seen in every family after a member survived a stroke. Almost all of the families perceived that there was at least one family member who attended to a stroke survivor. They stated that it was not like the agreement of who was going to be a caregiver, but it was automatically assumed. For instance, if the stroke survivor was the husband, then his wife took the role of a primary caregiver. When one member of the family became the primary caregiver, the other family members helped him/her to care for the stroke survivor according to their ability and suitability.

Additionally, roles and functions in the family, particularly those formerly of stroke survivors, were changed as a result of a stroke. The physical and cognitive impairments caused the survivors unable to perform their roles perfectly. Consequently, the survivor's previous roles and functions in the family were transferred to or replaced by other remaining family members. For example, sons or wives partly performed activities which once had been done by stroke survivors. Sharing previous functions of stroke survivors and household tasks was regarded as “working together or helping each other out.” However, there were some works which were gender-specific, especially the kind of works that needed a lot of strength to do, and this would then go to a male family member. As a result of changes in roles and functions, roles and functions of stroke survivors in the families were reduced while some family members’ responsibilities increased. For the second, the third, the fourth, the seventh, the ninth, and the fourteenth families, whose stroke survivors was a husband, his roles and functions were transferred to the wife, as some explained:

> Since he (a stroke survivor) has got a stroke, he cannot make any decision, which was once his role. Therefore, when some matters occur now, I will discuss them with my mother, and then we jointly make the decision. The role of a decision-maker has become our responsibility. … He (a stroke survivor) and she used to go purchasing goods for the store together, but after he had a stroke, my mom had to take care of both him and the store. Then it has become me who has to go out to purchase goods for the store. He (a stroke survivor) used to help me with some jobs such as keeping the house clean and sweeping the leaves around the house. When he cannot do it, I do it alone. (The fourth family)

> Now, I am responsible for everything. Everything! Like never before. I never realized that. I knew only my duty was to send money to the mother every month. I was confused as to how it happened? Why me? But now, I realized that if it is not me, who else will do it? (laughing) In the past, she (a stroke survivor) worked and earned enough money for the whole family. Right now, this duty is transferred to me. (The tenth family)

Likewise, for the thirteenth family, there were three members living together in the same household. When a member had a stroke, the survivor's household roles changed and the main responsibility went to her husband and a niece:

> We replaced her duties (a stroke survivor's household duty). … She (a niece) does it, too, such as washing clothes. As for decisions making, she (a stroke survivor) used to make a decision by herself, but not any more now. At present, I am the one who makes decisions. I am a male, but I buy utilities for the kitchen, too. Formerly, she (a stroke survivor) took care of this, while I did not do anything much. Ever since she has a stroke, all of the roles came to me such as offering foods, materials, and money to support the temple, or buying food to offer to the monks. (The thirteenth family)

The stroke survivor of the twelfth family used to perform the mother's roles fully. That included taking care of the son such as preparing food, studying, sending him to and picking him up from school. After she had a stroke, she could not perform such duties. Some of her duties were shifted to her husband or assigned to other people to do:

> Formerly, my wife (a stroke survivor) sent him to school and picked him up after school. After she had a stroke, I have more works. Some duties she used to be in charge of, I have to take over them, plus my own works. … The son realized that the mother had a stroke, but he did not discuss it with the mother and turned to discuss it with me. (The twelfth family)

Moreover, many families, which used to have the survivor as the head of the family, mentioned that although the stroke survivors were unable to fully perform this role in the family, they still kept the position of the family leader for them out of the respect for the husband or the father:

> My father is still the head of our family, we perceive that, but he just performs less work. The mother earns the living for the family now. She is a merchant and does everything instead of the father. But mostly, my father makes the decision. Whatever he used to do, he still does it as much as he can. For example, as for purchasing rice, he gives money to buy it because he cannot go himself. Or, he is responsible for paying for community funerals. (The third family)

> … We let him do some of the family's roles. Particularly he is still the head of our family, but he had less performance. My mother and I have more responsibilities because we take over his previous roles. But, my mom takes more than me. For household responsibilities, I think she has a lot, both food preparation and almost every matter in the family. It is now like my mother plays the father's roles, too. For example, sometimes there are meetings for the leaders of the community, and my mother attends the meeting. I go to the funerals sometimes on her behalf. (The ninth family)

Functional disabilities resulting from a stroke affected the survivors' ability to perform their previous roles and functions in the family. They also made the survivors dependent on constant care from family caregivers. Consequently, family responsibilities of being caregivers also increased.

Increased Family Responsibilities of Being Caregivers

Regarding chronic disabilities of stroke survivors, responsibilities of families were increased as they had to perform many caregiving tasks for the survivors. Some family members took a long-term role of a primary caregiver, while others participated in caring activities. As a result of increasing family responsibilities, all families perceived that they deteriorated their physical and psychological well being. However, at the same time, taking this role provided them with a chance to repay what stroke survivors had done for them before. Therefore, participating family members perceived that taking the family caregiver role was mixed with both positive and negative experiences.

Being family caregivers, participating families stated that they had to hold a lot of care duties, which are related to the level of impairments of the survivors. They explained that the more the stroke survivors were impaired, the more tasks they had to do. In general, primary caregivers were a main person who assisted the survivors in many daily living activities such as bathing, preparing meals, feeding, as well as specific activities related to stroke survivors such as rehabilitating, preparing medications, and accompanying them to see the doctors. Even though giving a long-term care to the survivors became routine activities, primary caregivers still had activities to do all day and night. The primary caregivers of the first, fourth, seventh, tenth, eleventh, and thirteenth families provided total and 24-hour care for their survivors due to complete dependency of the survivors. They said that when they started to be a primary caregiver at home, they had a lot of care activities to do since early morning until late at night. It seemed to them that they had very little free time, particularly in the first three to six months of caring because they were still unfamiliar with caregiving tasks, which were new for them. Therefore, they spent all their time completing the tasks. For example, the first family stated that during the first year of caring for their mother, 24 hours were devoted to caregiving duties. They started doing these activities at as early as 5:30 in the morning, starting from giving the patient a bed bath for around 1 ½ hours, then preparing blenderized diets and feeding her with medications, performing her passive exercises, turning her position every one to two hours, and so on. In addition to giving care activities, they still had to do household chores. As a result, they had to do a lot of activities in one day. Even though one year of caring eventually enabled them to settle these duties, they still performed the same quantity of activities each day. This situation was similar to other families such as the fourth, seventh, tenth, eleventh, and thirteenth families. These families expressed the same sentiments that their responsibilities had increased since they were family caregivers, as some of them stated:

> … I have a lot of works to do. During the first six months of caring, I started caring activities in the early morning and then every one to two hours. While doing those activities, I had to do my housework. One whole day was spent on these duties. Umm! One year later until now, it seems to be better because I get used to these activities and can set time to complete all duties. But I still do a lot of work… (The first family)

> He (a stroke survivor) cannot do anything since he has got a stroke. We take care of him and do all of his daily activities that he was once able to do by himself. These activities require most of my time. Particularly when he came back home, my sister and I had care activities to do every one or two hours. When I finished this (one care activity), I had to do the next (another care activity), and it went on like this all day. Now, we have settled but still do the same activities. (The seventh family)

Even for stroke survivors who were able to partially help themselves, some families still thought that they took over more responsibilities since they began to provide care to the survivors at home. They reported that even though their care receivers could do some daily activities, they still helped in some activities such as preparing foods, taking a bath, and doing laundry, as well as staying nearby the survivors. Some participating families stated:

> … It's good for me that he (a stroke survivor) recovers and can do some activities. However, before I go to work, I have to prepare his breakfast. Around 11.00 AM, I have to come back home to prepare lunch and take a look at him because I let him stay home alone. I come home in the evening and prepare foods for my family members, including him (a stroke survivor). On Sunday, I wash his clothes, my husband's, my sons', and my own clothes. I do everything. … It is different from the past when he was still healthy. … (The sixth family)

As for the second family, the survivor's wife did daily tasks while his son performed physical therapy everyday and took the stroke survivor to the hospital for the doctor's appointment. Their responsibilities as family caregivers had increased as they described:

> He (a stroke survivor) wakes up in the early morning. That means my duties are started then. I turn on the television for him, and then I go to the market to buy some foods for him and also for selling. I prepare goods for selling and foods for him, give him a bed bath, go to the shop, and come back home to see him. All the time I have to do a lot of work including caring activities, selling foods, and doing household chores. I've done this since he first got the stroke… (The second family)

Being a long-term family caregiver changed the life of participating families because their responsibilities increased. They had a lot of work to do each day. This made them develop both positive and negative experiences regarding long-term caregiving duties and responsibilities.

A stressful experience of long-term family caregiving. When they had to provide long-term care to stroke survivors, and when they were getting older, many believed that being a family caregiver affected their physical health and caused them prolonged stress. In the present study, it was found that family members' ages ranged from 19 to 83 years, with the largest group of them being older than 60 years old, followed by those who were 51-60 years old. For primary caregivers, the average age was 52 years. Of these, seven were aged between 51 and 60 years old, while two were older than 60 years old. Moreover, they perceived that their health problems were related to the level of stroke impairments. For six complete dependants who relied on family members for over a year, their family caregivers reported that their physical health was worsened as a result of having to move or carry the survivors. They described symptoms including backache, knee ache, and muscle pain. Some of them got hypertension as well. The first family, for example, had a backache caused by lifting their stroke survivor every day. Similarly, for the fourth family, a primary caregiver had a backache and pain on her left leg, which was increasingly severe. During the time of the study, her pain symptom was so severe that she had to take polymedications and do physical therapy everyday. Likewise, a stroke survivor's daughter who also helped take care of her father had muscle pain because of helping her father move:

> I have a backache, and my older sister does, too. We take care of her (a stroke survivor), and we have to move and lift her everyday. Even though her body (a stroke survivor's body) is slim, she cannot move herself. So, we have to help her. I know that my back pain is caused by lifting her. Now, we need back support whenever we lift her. (The first family)

The same physical problems were also found with a 62-year primary caregiver of the second family. With regard to her responsibility in daily activities of the survivor who had gain a lot of weight after suffering from a stroke for several years and her own old age, she had aches in her knees and shoulders.

Apart from physical problems, some families also experienced emotional stress and tension as a result of doing caregiving responsibilities for a long period of time. Long-term care of stroke survivors at home caused some families, particularly primary caregivers, to develop stress. They stated that they were the persons who mainly performed routine care activities and they had to do these for a long period of time. Some of them felt that they had less support from others than they had obtained in the first stage of caring. In addition, many caregivers mentioned that their deteriorating health caused them to be easily exhausted and gave them stress. The second family, for example, explained that taking care of a stroke survivor, both day and night continuously without any holidays as in other jobs, and without knowing when it would end, caused prolonged tension:

> Ever since he (a stroke survivor) had a stroke, I've taken care of him. It creates tension, right? I could not go anywhere. Please imagine doing the same things for months or years and not knowing for how many more years it will continue. It has become an endless routine. It is different from working in other jobs where you can take Saturdays and Sundays off. No weekends! I must perform this duty everyday. (The second family)

In this family, the stress created by becoming a family caregiver also affected the stroke survivor's son. He experienced a dilemma between giving care and working his job because he felt that he could not perform both well enough. Thus, he was under stress because he felt he could not take care of his father as well as he would like to:

> I am the one who mainly performs my father's physical therapy and also the only one who delivers cooking gas tanks to the customers. If I am giving my father physical therapy and the customers call to place an order, I will have to stop the therapy immediately and do the delivery. On some days I can give him physical therapy for a short time… I cannot fully give my father physical therapy… I am the one who takes my father to the doctor's check-up appointment. If the doctor makes an appointment on Monday morning, I will be too busy as it is the time when the business is busiest. I will then feel distressed because I cannot take perfect care of him. (The second family)

Similarly, the fourth family took care of a completely dependent survivor for four years. During many visits the researcher paid to them 2003, it was often found that the nephew always stayed close by the stroke survivor and performed many care activities for him. However, since 2004, the researcher met only the survivor's wife and daughter who lived with and took care of the survivor at home. Never once did the researcher see the nephew in the house. They stated that during the first two years of caregiving, they did not feel any stress because the nephew helped them with all caring activities such as nasograstric tube feeding, bathing, cleaning, and dressing the tracheostomy tube. However, he stopped providing care one year after that. As a result, all caregiving responsibilities went to the wife and the daughter, and they had proved to be stressful duties. With tears in their eyes, they stated:

> I was tense! (stating firmly) Very tense indeed! I take care of him everyday. The person who used to help around here has not come any more. Not at all. He has changed completely. Sometimes I want to sleep but I just could not sleep. When I have a lot of tension and cannot bear it any more, I go away to Mae-Tang. I must go. But the feeling that 'it is my duty to take care of him' is still in my heart, and I cannot desert him. Only I can take care of him. (The fourth family)

For the ninth family, stress that was caused by long-term care for a six-year stroke survivor occurred to the stroke survivor' wife. She said that providing long-term care to her husband was psychological stress for her, which manifested itself in the forms of hypertension and depression. She talked and cried while reporting that she had to do many activities for her husband, which lasted from days to months to years, and then forever. She was quite exhausted. She had so many sleepless nights because she kept thinking about her family life and also her husband's condition. One day, she got sick with a headache, vomiting, and prolonged sleeplessness, which made her decide to see the physician. She found that she got hypertension and depression that needed regular treatment. That incidence made her realize her poor physical health and the need to seek medical treatments.

A rewarding experience of long-term family caregiving. On the other hand, taking the role of a family caregiver created a good experience among participating families. All of them realized that it was their chances to repay their loved one by performing this commendable duty.

Every family had taken the family caregiver's role since a stroke survivor returned home. They stated that caring for an ill family member was an instinctive role that came naturally, especially for women, dyad, or children. Accordingly, all of the participating primary caregivers were female and most of them were related to stroke survivors as being their wives or daughters. They felt that a couple, which shared a close relationship, should take care of each other whenever one of them got sick. Also, the daughters should provide care for their ill parents:

> He is my husband. After he got a stroke, he becomes a disabled person. I didn't even have to think whether I would take care of him because I am his wife, and it is the responsibility of every wife to care for her husband. And so I do it. (The seventh family)

> I jumped into caring for her (a mother who had survived a stroke) when she was discharged. I didn't know why, but I knew only that I wanted to provide a close care to her. In addition, I am her daughter, the youngest one. Among her daughters, I have the closest relationship with her… I think it should be a daughter who takes care of her because she also is a woman. I can do everything for her. (The eighth family)

Participating families expressed in the same sense that they took care of their care receivers based on a willingness to care for their loved ones and thought that this role was a good opportunity to repay them. They also realized the value of the roles they had performed for many years. Importantly, many families referred to Buddhist teachings that enabled them to take care with the senses of happiness, faithfulness, and gratefulness, as some family members said:

> Never! I have never felt that he (a stroke survivor) is a burden. I do not feel like this since starting to take care of him. I used to do things for him more, but I have never ever thought that any is a burden. If I am asked whether I am tired or not, in the beginning, the answer was yes. However, just thinking that he is my father lets me be able to do anything. … If I can do anything for my parents, I have to do it, and I can do it without feeling that it is burdensome. It's my obligation. (The sixth family)

> Never! Never! Never gets bored. I am used to doing it (caring for a stroke survivor), and I have never felt bored with it. … She (a stroke survivor) is our grandmother, not other people. Now, she gets sick, and we can do anything for her. (The eleventh family)

> Even though I am not her biological daughter, she has nurtured me and raised me as her own daughter. I always think that she is my second mom. Caring for her is like caring for my mother. Every one should have and show gratefulness and gratitude, especially when one's parents get sick. (The thirteenth family)

The first family felt that taking care of their mother for a long time contributed to their being good-spirited. It was a good opportunity to be close to the mother because they had been apart from each other for a long time. Therefore, after her mother got a stroke in Bangkok, she moved her mother to her house so that she could take care of her. This family felt that the longer the stroke survivor could stay alive, the happier they should get:

> I think it is the time to take care of my mother (a stroke survivor) after we had lived apart for a long time. … I intended to take care of my mother. She is the most important person. I refuse to go anywhere with people and told them that I have to take care of her. I do it for her ever since she has a stroke almost two years ago.

> Never have I felt tired or bored to do this for her. I speak with my older sister that I wish my mother will stay with us for many years to come, and she can even live to be a hundred years old. We can take care of her. (The first family)

Long-term care of stroke survivors at home increased family responsibilities. Even though the responsibilities could be stressful experience, positive perceptions due to caregiving were felt by many families. Moreover, families also expressed the other side of their experience that the quality of the relationships among the family members improved as a result of this.

Increasing Family Cohesion

A change in family relationships was evident in all participating families in the form of increased family interactions and communications during caring for the stroke survivors, which helped establish closer family relationships. Family members, who lived in the same house or in a close proximity, illustrated their concern and pooled efforts to support the survivors and the families.

From the researcher's observations, good relationships, with affection, closeness, and sympathy were likely reveled in all families in this study, which could be seen from their verbal and non-verbal expressions. Congruently, a majority of families (13 families) also identified that they perceived an improvement in the relationships among family members during caring for the survivors at home as evidenced by more communications, visits, and contacts via telephone calls. For example, the first family, which was a nuclear family, felt closeness to the stroke survivor and the oldest sister after caring for the survivor at home in Chiang Mai. They described that her mother and oldest sister lived in Bangkok for over 30 years and seldom visited each other. Taking care of the survivor at her home in Chiang Mai became a good chance for all of them to live together, lend their hands to help one another, and express their mutual love and concerns by sharing caring activities and financial responsibilities. Likewise, the second family, which was an extended family, harmonized in caring situation. Even though each family member had his/her own responsibility, all of them had been involved in looking after their stroke survivor in the forms of giving money, cooperatively solving problems, and frequently visiting one another. They perceived that these actions improved the relationships in the family.

The fourth family had the same experiences as the two families mentioned above. Four years of collaboratively managing caregiving for the father who survived a stroke, their family, especially the survivor's daughters and son, had become closer to one another, which was differed from what they had been in the past. All of them had participated in taking care of their father directly and indirectly since their father got sick. The daughter said that they felt good with her son from his regular assistances. Besides, increasing family cohesion resulting from long-term caregiving was also manifested in other remaining families. One participating families stated:

> … My grandmother has become the center of our family (a stroke survivor), as all of our relatives in Chiang Mai and Bangkok frequently come to visit her (a stroke survivor). Those living in other places in Chiang Mai come every day to visit my granny while those in Bangkok come here every month. During the week, they call us very often to ask how she is doing. She (a stroke survivor) is our center. … They come here because of her. That's good! It brings us closer than ever before. I had never seen some relatives before she was sick, but when they knew the granny has been sick and needs long-term care, they all come here and we have a chance to be closer. … (The eleventh family)

> … I feel that a house is a home, not just a house. My mom comes to stay with us. … My relationships, particularly with my dad, have been quite improved. He calls us every month and sometimes gives us some money. You know, he never did that before! Moreover, my mother and father also get back on good terms. My mother

> said that she forgives him. … He shows his concern about my sister (a stroke survivor) and helps us out. … One day I talked to my friends that I ran out of rice and would like to go to buy it. Then my mom asked me 'will you go to Nim See Seng?'(นิ่ม ซี่ เส็ง). I was bewildered. She said that my dad sent me rice. I feel so good about him now. (The tenth family)

For the ninth and eleventh families, they still gained something good from caring for the survivors because it brought everyone in their families to be together and improved family interactions through joining family activities such as having a meal together, talking with each other, and spending time together. They reported:

> I think there's still something good from this incidence. Before, we lived on our own and didn't pay much attention to each other. We never asked 'what's going on with you?,' or 'do you have a meal yet?,' or any other questions showing our care. We never had a meal together. If I was hungry, I could eat first or if I wanted to eat something, I went to get it by myself. But now, everything has changed. We have a meal and talk together everyday except the day I have a class. Sometimes we buy something to eat together. And for these few years, I've given my father haircuts at home as it's difficult for him to go to the barber's. Cutting his hair at home is much easier and that makes me and my dad feel good. (The ninth family)

As a result of caregiving duty, participating families perceived that the family relationships had improved. They indicated that all members in the family took part in caring for the survivor, which created their closeness and good relationships with each other. In addition, care for stroke survivors at home caused all families to change their roles and functions in the family, and this was perceived as another worthwhile experience by family members.

The chapter reflected families' giving long-term care to stroke survivors at home which resulted in the change in the entire family. They confronted with stroke survivors' life changes and perceived them as facing with unexpected stroke attacks, psychological and emotional alterations, and also living with a permanently disabled family member who required continuing care at home. Long-term caregiving also burdened family finances, decreased family social activities, and altered roles and functions in the family. Moreover, after becoming family caregivers, family responsibilities increased because they took more care duties. Some families felt that providing care to a stroke survivor could be very stressful and frustrating. In contrast, giving care to stroke survivors was a wonderful chance for families to do a good thing together and this became an extremely rewarding experience. All in all, the family cohesion improved as a result of taking care of the stroke survivors.

Discussion

The experiences of the families that provided long-term care for stroke survivors were demonstrated as encountering having a disabled family member and changes in family life. These included encountering with having a disabled family member, stroke survivors' psychological changes, and acceptance of having a disabled family member. The whole family's life was also affected by family financial burdens, family roles and functions changes, decreased social life, and increased family cohesion. In addition, being family caregivers, families took more responsibility and perceived being a long-term family caregiver as a stressful yet and rewarding experience. Thus, long-term care affected the entire family. Such experience could be explained that because the family is seen as an accumulation or sum of the individual family members, all changes and ways of family organization involved all members in the family, with regard to interconnectedness of the family system rather than separateness (Friedman, Bowden, & Jones, 2003, p. 153).

Data derived from this study support some studies that explored the caregivers' experience with long-term stroke care and reported that they dealt with the uncertainty and the initial shock of the sudden onset of a stroke situation (O'Connell & Baker, 2004; Smith et al., 2004). They described this experience as fearing of stroke patients' death (Smith et al., 2004), and believing that it was the end of the patient's life (Connell, Penney, & Owen, 2001). When the time of caring passed, many families mentioned that they got familiar with the survivors' conditions they had seen for many years and recognized that there were permanent changes that occurred to stroke survivors. This experience differed from the experience in their initial stage of caring, which included shock, doubt, and uncertainty. According to McDaniel's study (1976, as cited in Goldstein & Kenet, 2002), the family's responses to changes followed in four stages as shock, refusal, attempt to understand the cause of the sickness, and acceptance of the changes and modification of the family life, which was in accordance with the experience of participating families in this study. In addition, this finding was in congruence with that in a study of Whitney (2004) which revealed that when families provided long-term care for adults with Parkinson's disease, they could cope with the situation and finally accepted it. They could then adapted to their care receivers' limitations and also were certain that their lives would never be the same. However, very specifically, the way Thai families cared for long-term stroke survivors and accepted their disabled family members could be explained by the teachings in Buddhism such as "letting go" and "beliefs in fate." This was clearly evidenced when stroke survivors' families stated, "what ever will be, will be" and "it is normal to get sick because of the old age." Such evidence of acceptance was cited in a study of Sethabuppha (2002) that Thai families caring of psychiatric patients at home believed and accepted that this was their karma or fate they had to follow, which was based on the Buddhist principle. Moreover, long-term caregiving encouraged many families to "accept" the current family situation. Numerous research on family caregivers and caring for chronic patients, particularly in the Thai context, also reported similar findings such as Atchara Sukorntasub, Laddawan Singkumfu & Rattanawadee Chontawan (2002), Nanthaporn Srinim (2002), and Junda (2002). Such studies indicated that caring for a member with a chronic illness provided caregivers with a chance to accept the event that occurred in their life and realized that the sickness was unavoidable and in fact a common life situation. These findings confirmed the influence of Buddhism in Thais' way of life. By using the family system theory, it can be explained that as family life is an open system, which constantly interacts with the external environment, family life is interconnected with the social-cultural system (Friedman et al., 2003, p. 155).

Participating families also faced stroke survivors' psychological and emotional changes such as loss of self-confidence and fear of death or abandonment, which resulted in their inability to live alone, inability to accept their disabilities, and rapid changes in emotions or mood swings. This experience was also described a study of Smith et al. (2004), reporting that the caregivers of long-term stroke patients felt that their care receivers were less able to cope with their conditions, suffered a loss of confidence, and felt that they were unable to live alone. They also commonly reported behavioral changes in the patients, which ranged from frustration and quirkiness to anger. Similarly, in this study, even one year after stroke, the survivors still had physical difficulties, loss of activities or roles in the family or workplace, and slow level of recovery. Therefore, it was difficult for long-term stroke survivors to cope with many changes that occurred in their life.

As regards changes in family life, all families mentioned the impacts of long-term caregiving on the financial status of their families. Every family spent a lot of money caring for stroke survivors, particularly in the first year of caring. Such finding was similar to the findings of the studies conducted by Boonyarattana (2002), Nanthaporn Srinim (2002), Saowaluk Natechang (2002), and Surawattana (1999). These research indicated economic impacts from a stroke on families during the first year of caring. Furthermore, data from this study highlighted payments need to prepare the home to accommodate caregiving and to be a care setting, which was consistent with a study by Smith et al. (2004). These researchers reported that after discharge, families perceived that restructuring their home for taking care of stroke survivors required funding application that created a financial problem. Moreover, family financial situation was continuously affected by long-term care for stroke survivors due to loss of family income from stroke survivors permanently and responsibility for covering the survivors' medical and care expenses. In this study, all of the survivors who used to work were unable to get back to work after getting a stroke. Therefore, it contributed to participating families' permanent loss of part of the family income. This result was also in accordance with a study of Palmer and Glass (2003) which showed that long-term stroke made the family face financial strain due to caring expenses and loss of income both temporary and permanently.

Findings derived in this study also revealed chances in the family's social activities which decreased as a result of long-term care due to movement difficulty of stroke survivors and inconvenient public transport systems. The data yielded support to a study by O'Connell et al. (2001) which indicated that family caregivers and stroke survivors faced a problem with transportation system, which was considered inadequate and unable to sufficiently accommodate the survivors' physical disabilities. This finding reflected the limitation for stroke survivors and families to share outdoor activities together.

As family is a system, the presence of a serious or chronic illness in one family member usually has a profound impact on the total system, especially on its role structure and the carrying out of the family function (Friedman et al., 2003, p. 9). This notion can be used to explain the findings of the present study. Family members had to play one additional role of being a family caregiver while also taking over previous roles of stroke survivors that were shared among remaining healthy family members. The data confirmed that caring for an ill family member is still one of basic function in Thai families (Phengjard, 2001). Moreover, participating family caregivers expressed that the care provided for the sick family member was based on the feeling of love, concern, merit making, and willingness to care for their loved ones. It indicated that Buddhist teaching still plays a significant role in Thai society as it is widely believed that the younger generations must show gratitude by caring for their parents and elderly members of the family when they get sick or old (Bhassorn Limanon, 1995). Based on these positive feelings and attitudes, all families in this study could continue their roles even though they had to provide long-term care. In addition, altered roles within the family caused by transfer of the previous roles of stroke survivors were relevant to a study of Smith et al. (2004). These researchers found that alteration in roles and functions within the families after caring for stroke survivors was a major issue for the family. This involved reversal of former domestic male/female roles and additional responsibilities. Also, the finding was consistent with another work conducted by Jariyawat, Usaporn, Chutima, Ratrae, and Orachorn (1993) who discovered the switching of roles in Thai families caring for HIV/AIDS patients who had to take family roles as the head of the family, the decision maker, or the breadwinner of the family. Friedman et al. (2003, p. 326) point out that this switching restores the stabilizing properties of the family when roles pattern threatens to break down.

Participating families also experienced increased family responsibility of being family caregivers. It can be explained that even though care for an ill family member was a basic family function, an occurrence of stroke was a sudden event in the family. Moreover, a stroke changed stroke survivors to be permanently disabled persons, who required care from their families. Thus, performing caring tasks was unprepared, new, and huge tasks for all families that inevitably caused them to have more responsibilities. The same finding was also found in the study of Robinson et al. (2005) that caring for a family member with stroke caused radical family life changes including extensive responsibility shifts, in which the carer felt he or she was doing it all, with new domestic and financial responsibilities, and also responsibility for the care. Moreover, health problems normally occurred to family caregivers including ache and pains in many parts of the body such as backache, knee ache, back pain, and some developed high blood pressure after caring for a stroke survivor. It could be explained that a stroke was a chronic disease that caused permanent deformities to stroke survivors and made them need continuous physical and mental health care for a long period of time. Therefore, caring for a stroke survivor for a long time required dedication of family members, both time, physical power, and mental power, which created physical exhaustion and also caused health problems to the families (Junda, 2002; Saipin Kasamkitwattana, 1993). In addition, getting older can cause family members' physical deterioration and health problems such as ache, pain, weight loss, tiredness, and exhaustion (Saowaluk Natechang, 2002; Teel, Duncan, & Lai, 2001).

However, the participating families in this study also reported that long-term care was a stressful experience. During the early stage of caring, families often experienced significant stress because they lacked role preparation and necessary training. After the caring had gone on for a period of time, physical health problems of family caregivers themselves and multiple role demands were the issues most likely to cause family role strain. Friedman et al. (2003, p. 337) contend that the nature of role stress may change over the life of the caregivers and the dependent family members. Nevertheless, families providing long-term care had positive experiences rather than negative experiences. This finding is different from some studies in other countries, such as a study of Kanervisto, Pravilainen, and Asted-Kwike (2003) on the families caring for COPD patients at home. The findings demonstrated that although the family members accepted role changes because of the COPD family members' inability to perform their roles, members of the family felt stress, conflicts, and confusion on the roles in the family and perceived caring as burdensome. The different perspectives can be explained that in the traditional characteristics of the Thai family, the caregiving role is considered one of the basic family roles and family members tend to feel that they need to share assistance, concern, and care with one another (Narujorn Ittitherajarus, 1988). Moreover, the Buddhist religion plays an important role in individuals' and the family's beliefs about role performance. Families perceived an increase in family cohesion, virtue, gratitude, kindness, forgiveness, and more acceptances in the "law of karma" when having to provide long-term care to stroke survivors. As a study of Pramaha Boonpien (2002) showed, Thai families in Chiang Mai gave much significance to the past and the present lives that they continuously affected one another and one seen as one factor that hold the family life together. It is worth noting here that the families believed that they shared karma in their previous lives with one another, and their karma was the cause that they had to live together as a family in this life, so they should have only love, support, and assistance for one another in this life. Therefore, families caring for long-term stroke survivors expressed their appreciation of the roles rather than feelings of burden. They also perceived that long-term care became their spiritually rewarding experiences.

With regard to family cohesion and interactions with one another, this study found that relatives or kinship systems of stroke survivors' families were a social network with close relationships. Many families expressed that their family relationships had improved as a result of the concern and care they had for one another, as well as a result of the increase in time they spent together. Furthermore, the advancement of communication technology became advantageous to families as it allowed them to communicate and interact with one another more easily and conveniently. This connection contributed to the exchange of information and assistance that sustained the family life. Thus, family bonds were stronger through these interactions, which were a background of Thai families (Junda, 2002). In addition, this evidence could also be explained that even though the families' characteristics varied, all shared similar strong kinship system, which is a central family culture in Northern Thai families (Oranee Kapchai, 2002). Also, it can be pointed out that though at present the family lifestyle in Chiang Mai has been affected by the cultures of a newly industrialized society, the basic lifestyles of the people remained the same as they were mainly characterized by interconnectedness rather that separateness. This is a specific manifestation of the Thai family, with its own culture, custom, and religion that make the people who live together have an emotional closeness, relationship, and responsibility for one another (Pramaha Boonpien, 2002). As a consequence, it helps establish the positive outcomes experienced by the families caring for long-term disabled family members. The finding was similar to the study conducted on other groups of chronic patients. For instance, Ring and Danielson (1997) found that the family members of the COPD patients who required long-term care at home felt more emotional relations and stronger relationships among members of the family.

Moreover, it was found in this study that most of the families had basically good family relationships before providing care for stroke survivors. Even though some families showed previous family relationship problems, after long-term caring for stroke survivors, the relationship was changed to be better. Such finding confirmed that "power of love within the family" is the major character and a strong family tie of Northern Thai families. Likewise, Nangnoi Yanwaree (2002) and Hunsa Settabuppha (2002) discovered that although family caregivers took care of their chronic patients at home, the family was full of love and good relationships that created good understanding among members in the family. Family caregivers also recognized that caring for the sick member was "the duty of the family," which followed the principle teaching of Buddhism, the main religion among Thai people.