

**FAMILY BELIEFS SYSTEM SHAPING THE PERCEPTION OF
FAMILY CAREGIVERS' BURDEN IN TAKING CARE OF
STROKE PATIENTS, MANDALAY, MYANMAR**

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OF THE REQUIREMENTS FOR THE DEGREE OF
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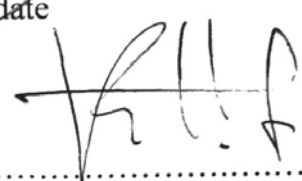
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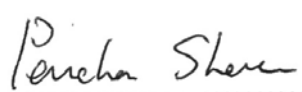
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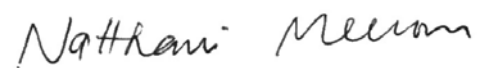
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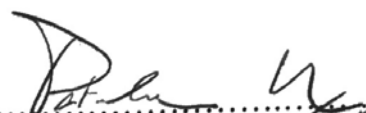
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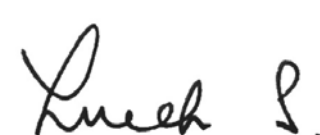
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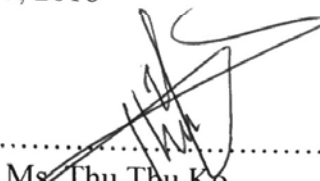


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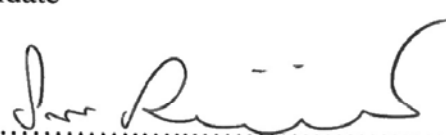
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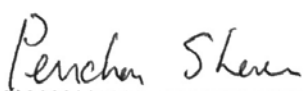
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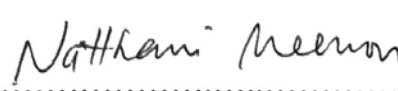
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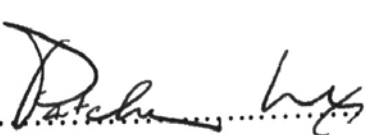
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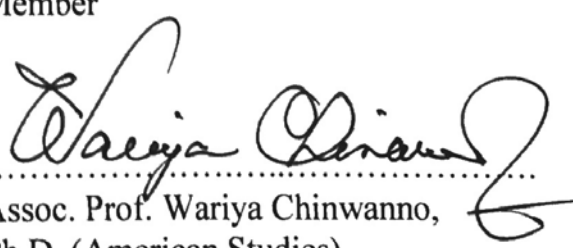
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FAMILY BELIEF SYSTEM SHAPING THE PERCEPTION OF FAMILY CAREGIVERS' BURDENS IN TAKING CARE OF STROKE PATIENTS, MANDALAY, MYANMAR

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ABSTRACT

Myanmar is experiencing an increasingly aging population along with the global trend of aging societies. The prevalence of chronic disease, especially strokes, is relatively high with an increasingly aging people. As strokes are a long-term disable disease, stroke patients need family caregivers to take care of them for long time. So, family caregivers have to sacrifice their own life by caring for stroke patients at home. They suffer some types of burdens such as financial, social, emotional and physical while caring. But, family beliefs are an important part of family caregivers' burdens, whether acknowledged or not.

This study aims to describe how the perceptions of burdens were shaped by the family belief system and how to cope with the burdens. Data were collected from a purposive sample of twenty family caregivers living in Mandalay, Myanmar, by using in-depth interviews and participant observation at the caregivers' houses. Particularly, interviews were carried out with nine daughters, five wives, two sisters, three husbands and one son.

When choosing a caregiver within a family, single, jobless and women assume the caring task. But, twelve out of twenty caregivers are married and they have to perform more roles than single people. Among the married caregivers, women have to perform more roles such as caring, doing housework, nurturing and working at the same time. If they do not receive enough support from other family members, they feel the burdens more than others. In fact, one female caregiver suffered family separation (divorced) because of reduced role sharing from her partner. In addition, caregivers who have financial burdens suffer from the rest of burdens at the same time because they have no time for social relations or no time for rest even when they are sick. Moreover, elderly caregivers who suffer from some kinds of diseases experienced many physical and emotional burdens. Hence, the family is one unit and they shared sadness and happiness with each other by filling one another needs. According to the family belief system, they perceive caring is family duty, care with love and respect, caring leads to 'good karma' or merit and suffering burdens is 'bad karma' or 'bad luck'. Finally, they use coping mechanisms such as doing exercise, visiting friends and doing religious things to reduce the burdens.

KEY WORDS- MYANMAR, FAMILY BELIEF SYSTEM, FAMILY CAREGIVERS, PRECEPTION ON BURDENS, COPING WAYS

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CHAPTER I

INTRODUCTION

1.1 Background

Aging society has become a global phenomenon. According to United Nations (2013), the rate of 60 years old or above people rose from 8% in 1950 to 12% in 2013. The projection is that the rate will increase significantly up to 21% in 2050. Whereas the significant growth of aging population is occurred in developed countries such as Europe and North America, the low and middle-income countries also experience the high rate of aging population. About 80% of elderly people are projected in low and middle countries in 2050 (WHO, 2012).

The several studies found that the prevalence of chronic disease is high together with increasing aging population (Center for Global Development, 2008; World Bank, 2007). Along with the increasing rate of elderly people, the epidemiologic profile of population structure changed as the main cause of an increase chronic disease especially in developing countries (Center for Global Development, 2008). According to WHO (2012), the burden of chronic diseases in older people in low and middle-income countries is higher than high income countries. Among chronic diseases, the prevalence of stroke in low and middle income countries is more three times than in high income countries.

Stroke is one of the major chronic diseases and it has been an important issue in the public health sector. The prevalence of stroke is relatively higher than other chronic diseases. According to WHO (2006), the prevalence of stroke was followed by heart disease and cancer all around the world.

However, unlike the other chronic diseases, stroke may influence directly the stroke patients' quality of life or activity of daily living since the disease can limit the stroke patients' body and brain functions. That leads the stroke patients to limit the activity of daily living and cause the disability. The several studies showed that stroke is a leading cause of long-term disability all over the world (WHO, Global Burden of

Disease, 2004; The Lancet, 2014). According to the Lancet (2014), stroke is the second cause of disabilities followed by dementia especially in low and middle-income countries.

Since strokes can generally lead to stroke patients' physical and mental disabilities, expected quality of life is usually low and poor. Specifically, stroke patients have to suffer physical disabilities due to limit the basic tasks of daily activities such as bathing, eating and dressing. Moreover, stroke patients suffer depression and isolation because they cannot communicate with family members and friends. In addition, they loss job and cannot do leisure activities. As stroke causes long-term disability, stroke patients need assistance from others such as family, close friends or paid attendants (WHO, 2006). However, mostly stroke patients take the long term treatment at home by living with family members. Therefore, stroke is critical issue for not only stroke patients themselves but also their family members (Legg et al., 2007; WHO 2006).

Myanmar experiences the similar situation together with the global trend about aging and stroke. Myanmar has undergone a demographic transition where the number of aging people increased. According to Global Health Observatory (2014), the percentage of the total population of Myanmar over 60 years old increased from 6.95% in 2002 to 8.15% in 2012 (WHO, 2014). The prevalence of stroke also increased when people get older and elderly stroke patients suffer more disability and poorer recovery rate than younger ones (Kato, Y. et.al, 2014). About three-quarters of all strokes occur in the elderly who are over 65 years old. The prevalence of stroke over 55 is high and the risk of getting stroke is more than double with every decade of age 55 (The Internet Stroke Center, Stroke Statistics: access in May 2015).

1.2 Significance of the Study Problem

The quality of life of stroke patients is low and poor. Beside the impairment of activity of daily living, the stroke patients suffer mentally and socially at the same time. For example, stroke causes the impairment of stroke patients' vision and speech. In addition, stroke patients totally depend upon the caregivers for activities of daily living. However, the caregivers could not totally understand what the stroke patients want to do, want to have and want to eat because of not clear speaking and poor vision

of stroke patients. Lack of communication with family members and no chance to do leisure activities add the negative feeling of stroke patients. The stroke patients may feel depression, guilt, anger and shame. As a result, the stroke patients response the caregivers inappropriate ways like throwing things and reject to have foods (American Heart and Stroke Association: Cognitive and Behavioural Challenges After Stroke, access in May 2015).

The majority of these stroke patients are provided physical and emotional support by close family members such as spouses or their adult offspring (Anderson et al., 1995). Family caregivers support a lot of things to stroke patients. The family caregivers take care not only for daily activities but also for health status of stroke patients like doing regular medication and rehabilitation daily. The family caregivers have to prepare the house by changing the structure and things like bathroom and bedroom for stroke patients. Moreover, family caregivers have to well prepare for cost of treatment because stroke is long term chronic disease. Mainly, the family caregivers have to support emotion of stroke patients due to severe impairment of physical movement (Sumathipala et al., 2011).

Stroke is a long-term disability and the family caregivers have to take care of the stroke patients for a long time. This creates the needs for a long term commitment from family caregivers. As a result, the strong relationship between family caregiver and stroke patient cause the burden of caregivers. Family caregivers are defined as kin such as spouses, sons, daughters or daughters-in-law who took care of the stroke patient and provided assistance for daily activities as well as provided emotional, social and financial support (Flewell, M. 2010).

Caring for stroke patients put social, emotional, health and financial burdens on the family caregivers. The family caregivers have not only great negative physical and emotional impacts but also financial and social burdens in caring for stroke patients (Carod-Artal & Egido, 2009). Some characteristics put the family caregivers burdens such as large impairment of daily activities, small number of caregivers and long length of day and night caring (Gbiri et al., 2014; McLennon et al., 2014). According to Tang et al. (2011), different caregivers suffer different degree of burdens because the family caregivers' burdens depend upon the age, education and degree of disability of patients. For instance, if the stroke patients are old, no knowledge

about health care and nothing can do for daily activities, the caregivers suffer more burdens especially physical and emotional strains.

Several case studies provided the burden of family caregiver in taking care of stroke patients in detail. The previous case studies usually mentioned about the four types of burden in taking care of stroke patients. They are financial hardship, lack of social relation, physical and emotional impacts. The four types of burden in detail case studies are as following mentioned.

1.2.1 Financial Hardship

There are several studies found that family members experience financial difficulties when they take care of family stroke patients for long time. For example, as the stroke patients need help from family member full time, the family caregivers have to reduce the working hours or quit the job for caring (Kovinsky, K. E, 2001). According to WHO (2005), if the stroke patient is a breadwinner, the wife has to work for long hours to cover the cost of living the whole family. It affects both the stroke patient and family members. For instance, the stroke patient could not go to clinic for treatment regularly because family members could not afford for transportation fees. Not only facing difficulties to pay treatment for stroke patient, but also difficult to pay for caregiver's own health care. The caregiver could not spend for own personal illness because of spending all money for the treatment of stroke patient (Anantato, 2005 p-102 & 103).

Nguyen, T. T. C. (2009) pointed out that the family members suffer the financial hardship when the treatment of stroke patients is more than saving money and daily earning. Moreover, if the saving money or daily earning is not enough for treatment of stroke patients for long time, family members have to sell assets, borrow money from relatives and submit properties like house documents to borrow money with the interest from the bank for long term treatment of stroke patients. As almost all earning money spend for stroke patients' treatment, the family members also face difficult to pay children education and hard to do family plans like cancelling wedding of family members. All in all, from the above previous studies, the family caregivers suffer reducing working hours, quitting the job, selling assets, debt, facing difficult to

take treatment both stroke patients and family caregivers and facing difficult to pay for children's education fees in financial hardship part.

1.2.2 Lack of Social Relation

The lack of social relation is associated with financial, physical and emotional burdens and all burdens cannot be separated individually. According to Nguyen, T. T. C. (2009), the caregiver could not ask any help and could not communicate with the relatives because of he or she could not pay the debt of relatives for treatment of stroke patient. Family conflicts make the isolation and loneliness of caregiver think like prisoner at home. Moreover, the caregiver has little or no time for communicate with friends and involvement in social events such as attending wedding ceremony. No chance to contact with friends and relatives cause the loneliness of caregiver. The caregiver could not go out and scarify the leisure activities because of worry to leave the stroke patient alone at home (Alnazly, E. K. & Samara, N. A., 2014). The family caregivers face difficulties to go away and travelling during holidays as they worry about stroke patients (Thommessen, B. et.al, 2002). By based on above previous studies, lack of social relation indicates that the family caregivers suffer isolation, loneliness, less or lack time for communication, less or lack times for participation of social events, less or lack time for personal time such as doing leisure activities and travelling.

1.2.3 Physical Impact

The negative physical status linked with emotional, social and financial conditions and overall, physical impact cannot be explained as solely burden. Due to lack of social or family support, the family caregiver takes responsibility alone the whole time. As a result, the caregiver feels weak or illness because of no time for personal care and sleeplessness (Anantato, 2005 p-102 & 103). As the family caregivers suffer financial and emotional burdens such as having debt and worry about money, the caregiver experiences eating and sleeping irregularly. Therefore, the family caregivers feel headaches and illness and admitted hospital (Nguyen, T. T. C., 2009 p- 89 &90). According to Alnazly, E. K. & Samara, N. A. (2014), as the family caregivers did not get enough sleep from caregiving at night; they feel restless and exhausted at the next

morning. The caregivers feel fatigue, body ache and joint pain because of carrying the stroke patients for daily activities such as dressing, toileting and bathing for day and night care in long term. Due to not enough time of personal care, the caregivers forget to take medicine for self. Therefore, the negative physical impact of family caregivers in taking care of stroke patients means the family caregivers suffer feeling illness due to irregular sleeping and eating, fatigue, restless, exhausted, body aches and joint pain.

1.2.4 Emotional Impact

The negative emotional status is directly related with financial, social and physical conditions and all burdens cannot be differentiated each other. The family caregivers feel sad for looking at love one suffering and disabilities for long term. At the same time, they worry about the cost of treatment and then feel stress and depressed (Nguyen, T. T. C., 2009 p-90). The caregiver who has less sleeping time or difficulty for sleeping suffers significant depression (Rittman, M. et.al, 2009). The previous studies of negative emotional impacts show not only family caregivers suffer sad, worry, stress and depressed but also they also experience anxiety, concentration problems, feeling hurt, guilty and angry (Evans et.al, 2014).

1.3 Perception of family caregivers in caring

These burdens can be seen apparently by other people or whether the family caregivers feel collapse or not are seen obviously by other people in caring of stroke patients. However, other unnoticeable part or inner minded of family caregivers such as perception or thinking about caring of stroke patients can fail to recognise. Despite these burdens seem to the family members carrying the heavy load, caring for stroke patients cannot be simply regarded as just burdens because of characteristics of family. Within the family, each family member shares beliefs, feelings, tasks and difficulties to pass the life by staying together as a same body. Like each part of body works together to harmonize as a single unit of body, each family member also needs to consistent to be a single unit to pass the difficulties time. For example, when one family member fails to do task or job of family due to suffering chronic illness, other family member fulfils the requirement of that family member.

The fulfilment of one family member needs including caregiving is a meaning of family. At least, family stands beside the family caregivers without contributing financial support is a value of family caring (Dressel and Clark, 1990). Existing meaning and value of family, caring is not a burden of family members because family caregiver takes care of stroke patient with love and respect. Caring for loved family member is a kind of family commitment to show family value. Passing the difficult situation together like staying with stroke patient all day and night for long time or looking at the loved one suffered pain and disability with full of love and kindness lead to feel the family togetherness and display of family warmth in the home (Pierce, 2001). Therefore, the family members take care of the stroke patients at home by giving best care of love, patient and kindness to fulfill the requirements of stroke patient at all.

Furthermore, the reason of why family members take care of the stroke patient at home is not only love and respect of family value but also influencing culture. Different cultures shape the different care and different responsibility of family member. By comparing Western and Asian culture, western people prefer living independence life such as older parents live alone and not living with their children. In Asian, parents live with children and individual within family have set relational sense of each member (Spitzer et.al., 2003). Therefore, the degree of family responsibility in taking care of parents is different according to culture. In addition, according to western culture, health is own responsibility. Children put limit of responsibility and not much involvement in caring roles of chronic parents. Even the children put limit of involvement in caring roles of parents, they do not feel any guilty about it. For example, elder chronic parents live in home care center and children visit that home once a week and it is a normal routine of caring of parents (Funk and Stajduhar, 2011).

According to Asian culture, taking care of sick family member is a kind of family members' duty and responsibility. For example, taking care of grandparents and parents are main responsibility of younger generation of family. In Japanese culture, the younger generations have to take care of elderly people because they are well respected and they did not bring any shame to the family's name (Miyawaki C.E., 2015). As the same as Korea culture, the reason of caring of elderly family members are respect, responsibility, harmonizing family and sacrifice (Sung, K. T.,1990).

Although Asian culture compose taking care of elderly people is the main responsibility of family, the main reason of caring is not same. According to Chinese culture, the caring responsibility of elderly is because of filial piety that starting from giving services and obedience to ancestor, parents, elderly people (Hsu, 1991). However, South Asia culture, the source of taking care of elderly people in family descends from religious beliefs such as dharma and karma (George, 1998).

Community members are watching the younger generation how they treat or behave the elderly people well or not. The family members takes care the elderly illness person within the family because it is private and just concern with family members. The taking responsibility of elderly family members is traditional and it is a job of family members (Miyawaki C. E., 2015; Spitzer et.al. 2003).

The role of each family member is also an important part within family. The family decides each family member's role based on culture. The family assigns the role of each family member such as what kind of tasks and how to do. According to Bracke, P. et.al (2008), caring is mainly for women and women have to take more responsibility than men. For example, if the woman caregiver is a married woman with children, she takes more than two roles. That woman caregiver has to take care of illness parent and children and at the same time she has to do job. If she doesn't have any support from family member or spouse in such kind of situation, that creates conflict within family (De Pasquale et al., 2015).

Even though the family members conflict each other in taking care of stroke patient for long period, the family caregivers can manage the feeling of being overwhelmed with physical and emotional things by religion. The caregivers feel worry and anxiety because they watch the disability of loved one and feel afraid of what time losing. The caregivers who believe in religion feel peaceful mind and receive the strength to endure the painful and tired situation in taking care of family chronic illness person (Pierce et al; 2008). According to Heo and Koeske (2011), caregivers who have deep beliefs in religion can get power and hope for the future in taking care of stroke patients. The beliefs in religion can also support physical and emotional status of caregivers. However, the degree of beliefs in religion depends upon the ethnicity. Different ethnicities have different degree of religion beliefs and different reducing level of physical and emotional strains.

Particularly, Myanmar is a country of religious based on culture especially Buddhism. People in Myanmar think that taking care of illness elderly people in family is a kind of showing love and gratitude. Thus, the family members do not think that taking care of chronic illness parents is a kind of burden. Moreover, mostly Myanmar families are single families and children live together with their parents at home. Therefore, the family members take care the parents at home when they suffered chronic illness like stroke. As Myanmar is based on Asian culture, women take responsibility of caring of family illness person. As caring of illness family member is only a family concern, family members take whole responsibility of caring. Each family member helps and supports each other by taking care of illness person alternatively or separate roles within family. For example, one family member take responsibility of caring and others take financial support. To conclude, the family caregivers cannot think caring is a burden because of culture, religion and family support.

The main reason of this study is aim to study the perception of family caregivers' burdens and beliefs of family caregivers in taking care of stroke. By exploring the perception and beliefs of family caregivers in taking care of stroke patient, this implication also helps to more deeply understand the quality of life of family caregivers. There is no social intervention and caregivers do not get any assistance from social welfare such as caring knowledge and financial support that leads them to feel more burdens in long term caring process. This population includes in ignorant population because most studies and social interventions focus on the quality of life of stroke patients and ignore the quality of life of family caregivers. By looking at the quality of life of family caregivers, it helps to improve the quality of caring of stroke patients too.

When looking at the quality of life of family caregivers, there are a lots of factors determined the burdens of family caregivers. Both specific family caregivers' characteristics such as socioeconomic status and perception of family caregivers in caring of stroke patients decide the burdens of family caregivers. All in all, by understanding perception on burdens and perception on caring beliefs of family caregivers, the policy makers are easy to decide how to establish improvement of quality the life of family caregivers.

1.4 Research Questions

Main Research Question

- How are the family beliefs system related to the perception on burdens of taking care of stroke patients?

Specific Research Questions

- What kind of belief system concerning about taking care of stroke patients do the family caregivers perceive?
- What are perception of burdens and experience of the family caregivers in taking care of stroke patients?
- Which ways do the family caregivers use to cope with the burden?

1.5 Research Objectives

General research objective

To describe the family beliefs system shaping the perception on burdens of family caregivers in taking care of stroke patients

Specific research objectives

- To understand how family beliefs shape the view on the burden of family caregivers.
- To identify the perception on burden of family caregivers in taking care of stroke patients.
- To understand the coping way of burden of family caregivers in taking care stroke patients.
- To understand how family beliefs shape the perception on burden of family caregivers in taking care of stroke patients and how relate with coping ways.

CHAPTER II

THEORY AND LITERATURE REVIEW

The purpose of this study is to explore and identify the burdens of family caregivers in taking care of stroke patients. In burden parts, the financial hardship, lack of social relation, impacts of physical and emotional status are main burdens of family caregivers. However, burdens of family caregivers are influenced by beliefs of family system and to what extent of burdens received depends upon family caregivers' perception on belief system. To explore how the family caregivers perceive on belief system, the sense of mastery or locus of control of family caregivers showed the caregiver's perception by influencing own thought, family members and super natural power such as luck or fate. The beliefs of family caregivers depend on the caregiver's background such as family history, cultural, ethnicity and religion.

Not only the sense of mastery influences the belief of family caregivers, but also status of illness patients decides the burden of family caregivers. If patient suffers chronic disease with lack of daily activities, it adds the burden of family caregivers. The family caregivers try to avoid burnout by seeking help from family or changing the past job, eating and sleeping patterns to adapt with the requirement of stroke patients. Therefore, to identify the family caregivers' adaptation or coping ways in living with stroke patients, how the family caregivers act, think and accept on caring of stroke patients are very important.

The acting, thinking and accepting of stroke patients is connected with other family members because family caregivers interact with stroke patients and other family members or relatives by sharing their ideas, beliefs and feeling. Each family member fills the requirement of other family members and depends each other to pass the life difficulties together. Each family member has roles, duty and function to fulfill the requirement of family. Roles, duty and function may change according to requirement of individual needs in family. The distribution of roles and responsibility is determined by family belief system based on culture and religion.

2.1 Theoretical Consideration

The family belief system originally derives from family system theory. The family belief system is combined with sociological perspective and psychological perspective. To understand the nature of chronic illness and nature of individual and family, the family beliefs system explains well about family caregivers' burden and beliefs based on both psychological and sociological perspectives. Moreover, the family is a part in society and each family member is also part of family. Therefore, family caregiver is a part of family and cannot differentiate with other family members. As family caregivers try to help the stroke patients, he or she can seek help from others especially other family members when feeling tired or stress.

The family beliefs system points out that why the family caregivers suffer stress and burdens from the cultural, social and psychological aspects. In addition, the family system composed by roles and function is changing in different times and different situations. For instance, when a family is experiencing chronic illness of one family member, the role and responsibility of each family member are different. Different families have different beliefs which are descending from different culture and religion. These kinds of beliefs have great impact on construction of family system.

2.1.1 Family System

Family system theory points out that a family is a social system and it is related with culture, economic, political and historical factors. Unlike other social system, the family system has a strong relationship among the family members. Even if a member of family loss or even someone take the role or function of that family member, the new one is irreplaceable the old one (Aponte & Van Deusen,1981, Minuchin, 1974, Minuchin & Fishman,1981, Nicholas, 1984 and Umbarger 1983 cited by Deacon S. A, 1996). For example, as a father suffers stroke in the family, the eldest son takes responsibility of the father role in the family. Although he can fill the requirement of family financial status, he cannot take care other family members like a father.

To understand about the family system theory, the family structure is involved in an important role. There are several studies discussed about structure of family system based on Bowen's family system theory (Lesser, J.G & Pope, D.S, 2007,

p-106). A family structure is established as a pattern of relation and interaction among family members. Each family member has roles and styles to interact with each other. Although some aspects of family members are common in all families, some were strange with other families. For instance, although wife takes care of her stroke husband, mother-in-law comes to the house and sleeps on the floor near her son for caring the whole time. The wife feels strange because she takes care of her husband well and mother-in-law acts like she doesn't care about her husband well.

The family structure is divided into **subsystems, triangles, hierarchies and boundaries**. The basic characteristics of **subsystems** are age, gender and function of family member. Individuals, dyads such as husband-wife and mother-daughter and larger groups such as mother and three daughters are also subsystem. Each family member belongs than one subsystem and each subsystem has own function to perform. Therefore, individual learns different skills, roles and function and also has different level of power. For example, although a woman performed as a mother role and function for her children, she also has a responsibility of daughter role and function of her parents. In parent-child subsystem, the parents held the power and daughter follows the instructions of parents (Aponte & Van Deusen,1981, Minuchin, 1974, Minuchin & Fishman,1981, Nicholas, 1984 and Umbarger 1983 cited by Deacon, S. A., 1996; Falicov, C. J & Brudner-White, L., 1983)

Triangles means three persons within the family maintain the balance under difficult circumstances and time. However, the third person is emotionally excluded in conflict situation. The third person such as relatives or friends or professionals serves as to reduce the tension and conflict between two persons of subsystem. For example, if the husband and wife conflict because the wife does not give enough time the husband due to taking care of her sick parent, the third person supports them to decrease the tension by taking caregiving role alternatively. On the other hand, due to third person, the tension might increase and lead to family dysfunction. For example, as one family member takes responsibility too much and feels burden, which can create conflict in family. To solve this unequal distribution of tasks, the third person could make decision for reducing responsibility for feeling burden of caregiver and should not make any decision of adding burden of family caregiver (Aponte & Van Deusen,1981, Minuchin, 1974, Minuchin & Fishman,1981, Nicholas, 1984 and

Umbarger 1983 cited by Deacon, S. A., 1996; Falicov. C. J., & Brudner-White, L., 1983 & Gerhart, D. R., 2012)

Hierarchy is shown as power, authority and responsibility. According to the hierarchy system, the parents' power and authority influence the children. For example, high value of hierarchy in Asia, taking responsibility and role of family member base on authority of family system. If one family member is rich and born as elder children in family, he or she holds the power and authority in family like choosing who takes care illness parent. He or she just thinks that supporting money for stroke patient is enough, he or she does not recognize any effort of caregiver in taking care of patient for long time (Gerhart, D. R., 2012).

Boundaries are clear relation between family members and outsiders to maintain the family system. Some families have clear boundaries such as parents know what children like, need, want and don't want reciprocally. However, some ethnic minorities have not clear boundaries because of sociocultural context and these families live together with grandparents, parental siblings and their children and non-blood relations within the family. The family organized by open boundaries such as enough communication with the outside leads to good relationship among family members.

However, when individual is lack of differentiation or lack of solving the problems, this stress spreads other family members which is called diffuse boundaries. Therefore, family structure and function have to change to adapt the stressful situation. One example of diffuse boundaries is that if family caregivers feel tired and stress because of taking care of stroke patients for long time, other family members also feel like caregivers and try to help the caregivers to reduce the stress by taking caregiving role. When the family system is organized by rigid boundaries, the communication among family members is difficult. If there is no diffuse boundary among family members, the family caregivers cannot receive any support of family members to solve the problems (Serowa, 2010; Sommer-Flanagan J. & R., 2012).

Each substructure of family system has clear and specific role of individual family. The role of individual within family is a crucial to maintain the family system. Each family member takes various and different tasks to operate process and structural functions of family. The roles of each family member derive from status in family, individual needs, family's needs and cultural expectations. The young generation has to

fulfill the cultural expectation by taking care role of elderly people in family. The children are socially constructed as caring of elderly people is the duty of family members to maintain the cultural identity. For example, the children are taught like respect and help elderly people and caring of elderly people is role of family (Spitzer et.al., 2003).

The family members take different roles in different times and different situations when the role structure needs to change the requirement of a family member. The family role structure is composed under the culture and social contexts. For example, the role of woman in Asian culture is different from other countries. The women in Asia especially married women take responsibility not only own family like caring for children, husband and parents but also parents-in-law (Lesser, J.G & Pope, D.S, 2007).

2.1.2 Family Illness Beliefs System

According to Rolland (1987b), the perspective focused on not only the emotion but also social types of family member. Family Illness Paradigms or Family Illness Beliefs System talks about how the family caregiver perceived based on social and cultural factors in taking care of chronic illness person. This perspective mainly describes about **health locus of control** or how the family caregivers perceived in taking care of stroke patients, **multigenerational evolution process** or accessing the family past history to cope the burdens between nuclear and extended families, **ethnic and cultural background** or role shifting from one state to another before and after the period of difficult time and **assumption about etiology** or accessing the causes of burden.

There are four factors shaping the family illness belief system. Following four factors determine the ways of coping and adaptation of family caregivers during caring the chronic illness patients. The four factors are family's **sense of mastery over an illness, evolution of family illness beliefs, family's ethnic, cultural and religious beliefs and family's belief about etiology.**

1. Family's Sense of Mastery over an illness

Beliefs influencing the individual or family members determine the burdens or coping ways of burdens. The sense of mastery is a kind of accessing family basic

value system. The current relationship among family members depends upon belief system or mythology. The three locus of control are **internal locus of control, external locus of control by powerful others and external locus of control by chance** which are used to access the sense of mastery.

The **internal locus of control** is seen as belief or perception of individual about caring illness person. The role, duty and responsibility involve in the perception of caregivers. For example, if the caregivers perceive that caring illness family member is a basic duty and commitment of family system. Caring with love and respect shapes the caregiver's belief by internalization and that determines the burdens of family caregivers. This positive perception leads the family caregivers to handle stressful emotion and practical tasks efficiently.

The **external locus of control by powerful others** is a person who depends upon other people and tried to seek help from outsiders. The differentiation of self or problem solving accounts by others such as relatives or friends. For example, the caregivers believe that illness of family member is cured by doctors or the burden of family caregivers is reduced by getting help from other family members or friends. However, **the external locus of control by chance** depended upon the luck or fate. For instance, the family caregivers think that getting illness of family member is due to bad luck.

2. Evolution of family illness beliefs

The evolution of family illness beliefs is access the family past history or family genogram such as that family had same experience of difficulties in taking care of family member before. Role shifting, structure of family, communication within family and coping strategies can be understood by accessing the family history at the same time. For example, if the family members have previous experience in taking care of stroke patient, they know about the nature of disease and how to take care the stroke patient. The family can distribute the role of each family member effectively without having any conflict about caring. Moreover, this belief represents the family myths, taboos, rituals and catastrophic expectations to more understand difference between in the past and present situation.

By learning the past experience, the family members can reorganize the role of family member to solve the problem like one family member is taking responsibility

too much or not. A family has a certain standard ways of coping with any illness. However, the ways of coping are different styles and extent of adaptation is different. Some families shift the healthier direction but others move rigid or extend dysfunction.

3. Family's ethnic, cultural and religious beliefs

Ethnicity, race and religion determine family's beliefs concerning health and illness. This belief points out that different culture of various ethnic, racial and religious groups decide constitution of family, degree of responsibility, main responsibility of family member and role involvement for taking care of chronic patients. For example, in Chinese culture, the responsibility of taking care of chronic illness person is the duty of eldest son and daughter-in-law of eldest son.

4. Family's belief about etiology

This belief discusses about what caused the family members' illness. Each family member has own explanation of existence of disease or illness. This belief combines with current level of medical knowledge about the particular disease and family mythology. Mythology includes the punishment for prior misdeeds, blame of particular family member and sense of injustice. This blame can be the patient self or one of family members or genetic. For example, the main cause of stroke is the patient doesn't stop alcohol drinking even he has hypertension or the family member treats the stroke patient salty foods before getting stroke or the stroke disease descends from the grandparents and ancestors.

This blame cannot solve the problem and it creates conflict within the family members. Personal responsibility guides all facets of life including chronic illness. If family has the strongest beliefs on personal responsibility such as finding main reason of causing chronic illness, unsolved conflicts is occurred in family. The blame, guilt or shame cannot solve the conflict and that creates dysfunction of family system. This blame or family conflict adds the burden of family caregiver.

2.2 Burden related to Patients' Illness Status

The caregivers may suffer burdens in caring of chronic illness family person for long time. The status of chronic illness family member adds the burdens of family caregiver. If the nature of chronic disease is constant disability and causes death

immediately, this kind of chronic illness pulls the family caregiver to feel stress and burdens. Moreover, stroke patients suffer disease immediately. Family members cannot well prepare for role shifting efficiently when the stroke patients admit hospital because family has to change roles and functions immediately. Anyone in family cannot know when the stroke patient suffers disease worsen to what extent. As a result, the family caregivers feel worried about the uncertainty of nature of disease. On the other hand, the burdens depend upon the perception of family caregiver. If the family caregivers perceived on caring with love and gratitude is good, this perception pushes the burdens of caregivers to certain extent.

2.2.1 Burdens

Although the burden of family caregivers is not including theoretical part, burdens and beliefs of family system are related each other. If the stroke patients are breadwinner, the family members suffer financial difficulties because of job retrenchment. In the emotional part, the family caregivers suffer depression, stress and anxiety (Das, S. et.al, 2010). When the family caregivers take care the stroke patients, they have to adjust the work schedules, take leaves of absence and reduce working hours. As a result, the family caregivers lose the salary, lose promotional training opportunities and reduce in retirement savings. In the physical status, the family caregivers suffer illness, sleeplessness, depression and chronic illness (Collins, L. G. & Swartz, K., 2011).

Evans et.al, (2014) pointed out that family caregivers suffered physical and mental burdens when they take care the chronic illness elderly. The caregivers suffer fatigue, sleeplessness, hypertension and heart disease because of worry and living with patients the whole day for long time. The caregivers also suffer depression, anxiety, stress, concentration problems, feeling hurt, guilty and angry because they see the love one with disability and chronic disease for the rest of patients' life.

2.2.2 Patient Illness Status

Patient's illness status take one part of the burdens of family caregivers. They are **onset, course, outcome, incapacitation and level of uncertainty**. Rolland (1999) explained that there are two types of **onset** which are acute and gradual. Stroke

involves in acute onset because the family members have to make decision immediately such as changing role, preparing emotion and using outside resources to adapt the sudden changing situation within the family.

The progressive, constant and relapsing can be accounted into **course**. Although family members need to prepare the new caretaking and financial preparing in progressive course because patient suffers disease worsen over time, the constant course needs the same caretaking and no challenges for caregivers. However, in relapsing course, family experiences more or less strains alternatively between crisis and non-crisis period. The **outcome** is the nature of disease that can lead to death or shortened the patient's life. For example, the stroke disease can shorten the life. If the stroke patient has other diseases such as heart disease, hypertension and diabetes, this can lead the stroke patients' life to shorten and die.

Incapacitation is the measurement of disability such as degree of impairment of cognition, sensation, movement, disfiguring conditions and poor physical, mental and social status. The family caregivers experience more burdens when the stroke patients suffer combination of cognition and movement impairment. The family members need to well prepare the coping ways to avoid the feeling of exhaustion and family dysfunction due to **uncertainty of nature of disease**. For instance, the family members cannot guess the extent of disease such as what time does the stroke patient suffer the diseases recurrently. That recurrent can die the stroke patient or not.

People who suffer chronic disease have to pass the three phases of illness. Three phases are measured by time line of before and after treatment of disease. By understanding the time phase of illness, the family members need to change the role, functions and preparing the future family development plans according to demands of patients. There are three types of time phase which are **initial crisis, chronic and terminal phases**. In the **initial crisis phase**, the family caregivers try to adapt living with the patients and adjusted communication, relation and taking responsibilities among family members and outsiders such as doctors.

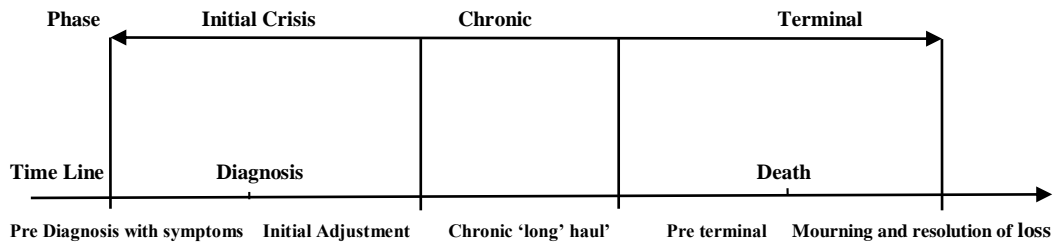


Figure 2.1: Time Line and Phase of illness, Source: Rolland (1994a)

However, during the **chronic or day to day living with chronic illness phase**, the family caregivers suffer burnout, conflict within family members because of long term care. Therefore, the family members need to try balancing the family system during this phase. In the **terminal phase**, family members need to cope with separation, death and mourning. After that, the family members re-organize the structure and function of family system beyond loss. Type, time and component of family functioning link with each other. The patterns of behaviour determine the individual's adaptation and beliefs of each family member.

According to Rolland (1987a), the nodal period (also called transition period) was the period between process of termination and initial crisis phases. All systems happen during transition period. The structure and function in family system change according to the transition period. For example, comparing to pre and post of family member illness, the tasks and roles of family members change a lot. Therefore, that family needs to reorganize according to the demand of help of family member illness to balance the family system. For example, before taking care of stroke patient, the family caregiver can go out to see friends. During taking care of stroke patient, caregiver cannot go out to see friends because caregivers feel worry about leaving the stroke patient alone at home.

2.3 Heading the Coping based on Family Belief System

The family caregivers think that caring of loved family member is not burden because other family members and people in society internalize belief of caregiver based on respective culture and religion. When the caregivers take care of the family chronic illness person with love and gratitude, this perception can reduce burdens to some extent or cannot feel any burdens. In addition, if the family caregivers are aware

about caring role and family member illness, this leads caregivers to less or no burdens. Depend upon how and to what extent the caregivers can perceive on caring based on family belief system, family caregivers react action such as accept or reject the caring of family illness person.

2.3.1 Three Coping or Adaptation

There are three kinds of coping which are **behavioral, social and emotional copings**. The three kinds of coping lead to positive adaptation or adjustment with people and outside environment. The **behavior coping** is a changing the daily actions or changing past habits or activities of family caregivers. The family caregivers try to adapt living with stroke patient by changing past job, eating and sleeping patterns. In behavioral adaptation, as the stroke patient needs the caregiver full time, the caregiver tries to take care stroke patient by quitting job, reducing working hours or taking unpaid leave. In addition, the caregivers try to adjust the sleeping pattern. Family caregivers can usually ask help easily from other family members during the day time, but at night mostly only the caregiver leaves to take care of stroke patient. Therefore, the caregivers feel sleeplessness at night and try to sleep in the day time. The eating pattern is also irregular because of changing sleeping time.

The **social coping** is seeking help from outside to adapt or to adjust the stressful situation. The family caregiver usually seeks help from family members, relatives or friends. For example, if the family caregivers feel stress, he or she calls friends and talks about that and asks advice from them. If the family caregivers feel tired and exhausted in caring, he or she can ask help from other family members or relatives. To get **emotional coping**, the caregivers seek help inside mind. The positive perception like caring stroke patient with love and respect is emotional coping. The obvious emotional coping is religion such as praying and going to church or temple. The caregivers who believe in religion feel peaceful mind and that feeling lead the caregivers to reduce the burdens. While they try to cope with burdens, two things of family trends which are family unity and separation are occurred.

Individual in family makes life changes to overcome transition period and tries to balance family system. Hence, two phases are occurred when each family member decides roles and responsibility shifting. They are **centripetal phase** or family

closeness or cohesion and **centrifugal** or family separation or low cohesion. The chronic illness leads the family to centripetal because each family member pulls on the family system by rearranging to adapt chronic illness such as assigning the role practically and effectively. For example, some families try to take care the stroke patients with love and kindness and each family member helps each other by sharing the treatment cost of stroke patient and caring the patient alternatively. However, the high demand and uncertainty of disease in long period cause the failure of balancing the family system (Rolland, 1987b).

2.4 Literature Review

2.4.1 Previous Literatures

According the cultural point of view, taking care of chronic parents is paying debt because parents look after the children in the past. Otherwise, chronic parent is a part of family member and caring is one division of family tasks to show a single unit of family (Albert, 1990). The family structure also decides the role and responsibility of family caregivers by following the rules of hierarchy system. For example, women take more responsibility than men in caring. At the same time, women receive help and support from family and relatives than men (Bracke, P. et.al, 2008). However, according to del Río-Lozano et.al, (2013), women did not seek help from others such as family members whereas men sought the external help and less took responsibility. Therefore, women feel burnout and social isolation than men. Same finding of both above studies are women take more responsibility for caring than men because of culturally constructed or hierarchy system.

There are some arguments about the responsibility of caring. For example, who has the most responsibility for caring of chronic illness person? The responsibility of caring chronic illness person changes from family to individual in long term case. Whereas degree of responsibility concern with gender, generation, ethnicity and social class, the family caring of chronic illness person is less and less because of weak of moral like less acknowledgement of sense of duty and responsibility within family members (Montgomery, 1996). According to Subgranon. R., & Lund, D. A. (2000),

caring was the main responsibility of family members and family members could not avoid it according to culture. However, caring with love, sympathy and attachment by family and community support at home is a way to solve the problems and difficulties of family caregivers.

On the other hand, less taking role and responsibility of family caregivers in caring of illness person cause high risk of burnout because of perception of avoidance. Family caregivers with low attachment avoidance and attachment love suffered fewer burdens (Karantzas, G. C. et.al, 2010). According to Friedemann and Buckwalter (2014), caring responsibility depended upon the culture and ethnicity. The caregivers think that caring guides family position and that leads to reduction burdens, less depression and strong family relationship. Different ethnicity determines the different levels of burdens, different coping and different behaviors. For example, African Americans suffer less stress, better physical status, less use of psychotropic medication and more belief in religion than Caucasian caregivers (Haley et.al, 2004).

The family caregivers' day to day living changes according to the condition of disease to overcome the crisis period. But, the family caregivers suffer crisis or burden when they are unaware the nature of disease and uncertainty of disease. On the other hand, the crisis reduces when the family caregivers have strong emotional ties like love and good relationship. This relationship or ties helps the family caregivers to reduce burdens (Strang V. R. et, al., 2006).

2.4.2 Myanmar Situation

Myanmar people live in cultural and religious constructed society. As most people believe in religion, caring of parents is not a burden for them because caring is the kind of repay the debt of parents and receiving merits. In addition, from the cultural point of view, Myanmar people believe that caring is family duty and they try to take care the patients by one of family members. In fact, these kinds of family beliefs may have some kinds of relationship with burdens in caring of chronic disable patients for long time.

Although a family perceived that caring parents with love and respect feel satisfaction and gratitude, that family can feel burdens because of lack of family financial saving or low family income for treatment of stroke patients. In addition, due

to nature of stroke is long and family caregivers experience lack support of social welfare, these add the family caregivers to suffer burdens. Furthermore, as stroke is a long term chronic disability disease, the family caregivers may feel collapse due to long time caring.

Moreover, this intercorrelation of burdens and family beliefs can explain multiple ways. When the burdens are considered in caring of stroke patients by family members, there are lots of factors influencing the burdens such as age, sex, marital status, education and occupation. In addition, it is very interesting to explore the burdens of family caregivers in caring process based on family characteristics like number of family members in a family and how much the family caregivers received support from family.

In fact, Myanmar people lived like close knit community and each family member helps each other. However, changing the lifestyle such as every family member has to work out to be enough the cost of living in family can impact the seeking help of family caregiver's burden among relatives. Therefore, it will be more meaningful to understand whether the family beliefs relate the burdens of caregivers or not by looking at different ways. As mentioned previously, various family culture and background such as characteristics of family caregivers and characteristics of family influence the burdens of caregivers.

2.5 Conceptual Framework

All the previous several studies are very well and explain about burdens and beliefs well. But, these previous studies conducted separately and didn't link with all the beliefs and all burdens at the same time. For example, when some studies focus on psychological burden and religion, others focus on physical and emotional burdens with health status of stroke patients. Therefore, by combining with burdens, health status of patients and family beliefs of caregivers, the whole picture of caring problems on chronic illness person will be obvious and clear to solve the problems. Therefore, the researcher develops the conceptual framework including burdens, illness status of stroke patients and family beliefs.

Under the family system, family is composed of structure and functions. The structure is divided into subsystems, triangles, hierarchies and boundaries. The **subsystem** is the family caregivers take more than one role and function. If the family caregiver is married woman, she has to take the role of caring patient and at the same time caring children and husband. The **triangles** is the third person tries to help decreasing the burden or solving the problems. The clear example of triangles is that relatives try to help the family caregivers to solve too much responsibility and conflict with other family members. The meaning of **hierarchies** is that caregivers take responsibility according to social status. The role and responsibility of caring are determined according to hierarchy such as caring is for women.

Boundaries are clear communication and good relation among family caregivers, each family member and outsiders. If a family has clear and good communication within family, the caregivers can seek help easily and do not need to feel burnout in caring of stroke patients. The **functions** are responsibility of family caregivers to maintain the family system and do not collapse in the difficult time. If each family member performs as the respected roles well, that family communication and relation are good. That prevents the conflict among family members even in taking care of family stroke patient with lots of difficulties for long time.

Although family caregiver and stroke patient live together under the family system, the burden of family caregivers depend upon the family caregivers' characteristics such as **education, age, gender, family past experience of caregiving** and **socioeconomic status** and extent of stroke patients' disease such as **onset, course, outcome, incapacitation** and **time phase**. If the caregivers take too much responsibility in caring of stroke patients, he or she can feel easily burnout. When caregivers are old women with less knowledge about caring, these characteristics add the burden of caring for stroke patients. At the same time, nature of stroke disease puts the burden of family caregivers. If the family has past experience in caregiving, the family caregivers know easily how to take care of stroke patients. At first, stroke patient suffers disease immediately and each family member has to change role immediately. Moreover, stroke is low and poor quality of life and a disable disease. Every day stroke threatens the patient life and family caregivers feel worry about uncertainty of nature of stroke.

The perception on burden of family caregivers is divided into four parts like **financial, social relation, physical and emotional impacts and support of caring knowledge**. If the family face difficulties for the cost of treatment of stroke patient, they usually borrow money and sell assets. It affects on future family development such as lack of money for paying tuition fees of children within family. Moreover, family caregivers feel lonely because stroke patients need them for activities of daily living all time. As a result, the family caregivers cannot contact with friends and relatives and they can feel prisoner at home. In addition, duration of care on stroke patient is long and the family caregivers suffer tired and sick. The family caregivers feel negative emotion like depression because they have to take care loved family member by scarifying their job, energy and time. Finally, the family caregivers feel burden if they do not know enough knowledge how to take care of stroke patients.

However, family belief system determines increasing or decreasing burdens of family caregivers. Depend upon how the family caregivers perceive the caregiving, stroke disease and role of caregiver, the burdens of family caregivers are different each other. The belief system is divided into three parts which are family value and beliefs of caregiving, family beliefs on stroke disease, sense of mastery. The **family value and beliefs of caregiving** is mainly discuss about how much the family take responsibility of caregiving according to culture especially that beliefs descend from family. Another thing is **family beliefs on stroke disease** that is describe about how the family believe on stroke disease. For example, although some families think that stroke is serious problem, some think stroke is not as serious as cancer.

The **sense of mastery** is subdivided into three parts such as **ability, social and cultural support and caregiving roles**. The **ability** is expressed by perception of caregiver. For example, the family caregivers take care the stroke patients with love and respect. The **social and cultural support** is perception on other family members and merit of family caregivers. For example, the view of family caregivers on support of family like financial and emotional support is social support. The obvious thing of cultural support is merit like the caregiving is a repay of debt of parents or karma. The last one of **caregiving roles** is described as perception of role of family caregivers. For instance, the taking care of stroke patients is own duty and responsibility because the family caregivers is daughter of stroke patients.

The **coping** of behavioral, social and emotional ways directly relate to increasing and decreasing the burden and also relate to belief system. The **behavioral coping** discusses about positive belief of caring. The family caregivers try to adapt living with stroke patients by changing behavior and daily activities. The family caregivers try to change the pattern of sleeping and eating according to status of stroke patient. The caregivers usually sleep during the day because he or she cannot sleep at night and other family member can help to care stroke patient during the day.

The **social coping** is seeking help and information about caring and illness from family members and friends. Family members try to help the family caregivers by taking roles alternatively. The family caregivers call the friends or relatives for talking about difficulties and burden of caring and can also ask advice to avoid feeling burnout. The meaning of **emotional coping** is family caregivers' positive thinking such as caring of stroke patients is because of love and respect. If the family caregivers seek the emotional adaptation by going church and temple or praying, that leads peaceful mind and of the family caregivers freedom of stress.

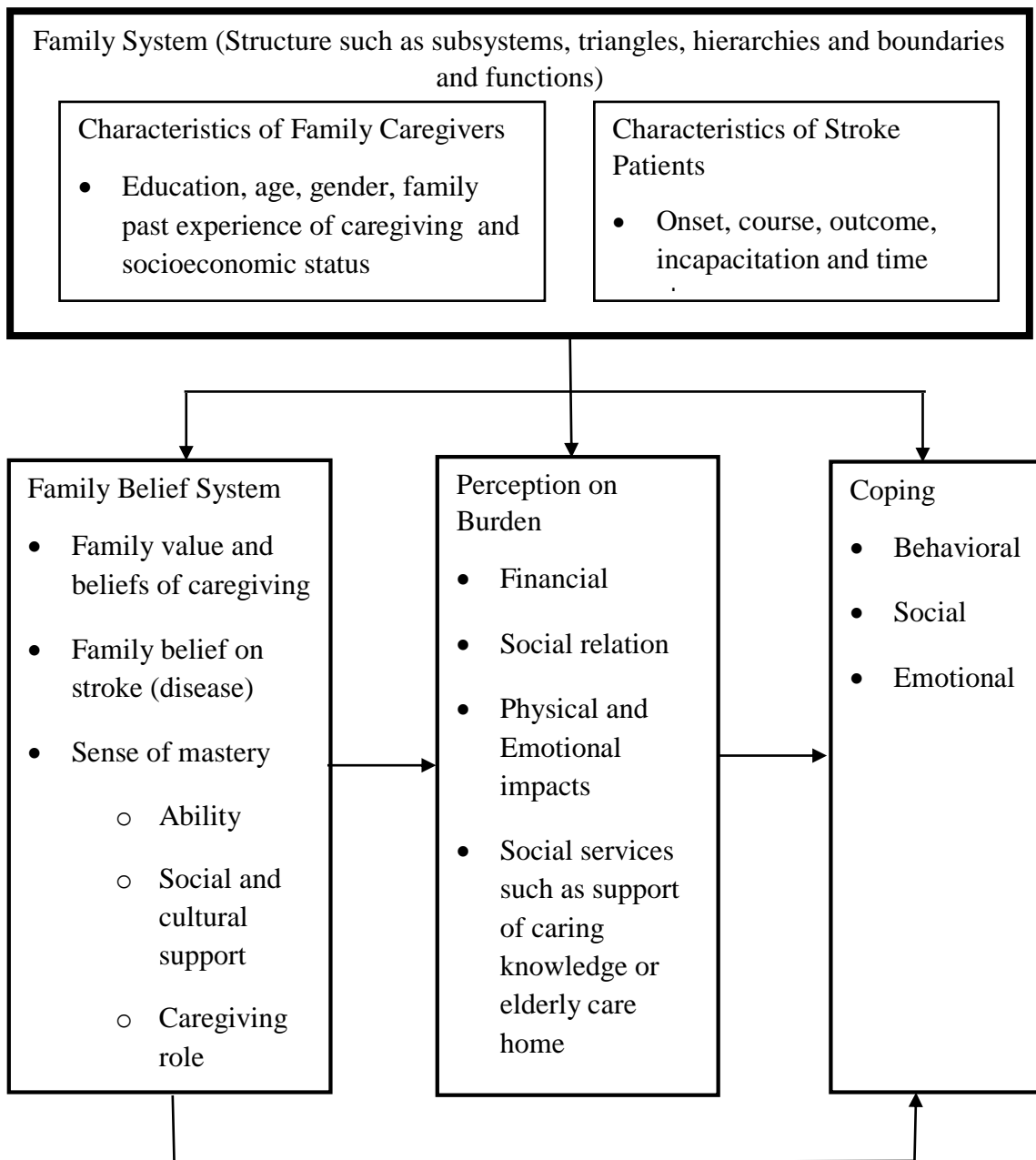


Figure: 2.2 Conceptual Framework

CHAPTER III

RESEARCH METHODOLOGY

3.1 Research design

This study aims to explore what the family belief system shaping the perception of family caregivers' burdens in taking care of stroke patients and how to cope their burdens. Therefore, qualitative, explanatory research is used to explore the beliefs of family caregivers in caring of stroke patients. The unit of analysis of this study is mainly focus on individual (Informant: family caregivers in taking care of stroke patients). However, as a group, family members' beliefs and family support affect the burdens of family caregivers. One of family members (Key Informant: living together with family caregivers and support them or stroke patients) also includes in unit of analysis because financial hardship does not concern only family caregivers. All family members suffer and include that burden. Therefore, family members contain as a part in the study.

3.1.1 Site Selection and entering into research field

Research is conducted in Mandalay, Myanmar. The research site is purposively collected according to the high mortality rate of stroke. Comparing with death rate caused by stroke in Yangon that was former capital city, the mortality rate in Mandalay was higher than Yangon. Although the mortality rate in Yangon stood tenth position of 2.1% of total death population in 2011, the rate in Mandalay stood fourth position of 2.8% (Ministry of Health Myanmar, Annual Hospital Statistics Report, 2013).

At the beginning, the proposed started point of entering into the field work is rehabilitation center in Mandalay General Hospital because some physiotherapists usually go home visits for physiotherapy treatment. Moreover, the researcher would like to conduct home-based study by following the physiotherapists who go for home visit. In reality, the researcher went to the Mandalay General Hospital after receiving approval

from Mahidol University's ethical committee for health social research. However, there were not any stroke cases admitted hospital and one stroke case in hospital is exclusion of research criteria. In addition, the researcher asked permission to the head of rehabilitation center to give addresses the old stroke cases by chasing these addresses to conduct the research. But, the address in the medical record files were not noted as full addresses and the researcher could not chase any old stroke cases in Mandalay General Hospital.

Fortunately, one of researcher's friends called the researcher she knew a physical therapist who was a master student and studying about physiotherapy in University of Medical Technology. She is also trying to conduct the research about the stroke patients and she introduced the researcher some of her participants. And then, some friends of researcher who are working in private clinics or INGO helped the researcher by introducing their patients. Hence, some participants introduced the researcher with their neighbors or acquainted people who are taking care of stroke patients at home.

Finally, the researcher received contact with a teacher from University of Medical Technology who is working in INGO for disable project now. He usually visits for physical therapy treatment for disable people in the suburb area of Mandalay once a month. Therefore, when he visited to the suburb area, researcher followed with him to conduct the research. Normally, the researcher went the participants' houses three times to get reliable and rich data. But, as three of participants in suburbs area are difficult to go and the researcher could not go there alone again, the visit time to the participants' houses is just once.

3.1.2 Sampling Methods

In the study, the purposive sampling and snowball sampling were used. Some family caregivers were chosen according to the recommendation of friends and teachers in University of Medical Technology who are working as physiotherapists in private clinics, government hospital and INGO organization. The researcher could conduct the different characteristics of family caregivers such as different levels of family financial status because the researcher went to not only downtown area but also suburb area in Mandalay by following the field work of INGO team. In addition, some

family caregivers introduced their relatives or acquainted people who also take care of family stroke patients at home. As the family caregivers or family members referred the researcher to other stroke caregivers and they were including the criteria of informants, the researcher conducted the study. Therefore, snowball sampling method helped to get rich information or data because the researcher could conduct the research with different level of family financial status. The researcher went home three times visit for informant interview and one time visit for key informant interview. The following table shows the criteria of informants and key informants and sampling methods.

Table 3.1: Recruitment process for informants and key informants

No	Sample Population	Inclusion Criteria	Sampling Method	Number of participants and number of visiting times
1	Informants (Family caregivers)	-Family caregivers who take care the chronic stroke patients for more than six months by spending more time, energy and effort than other family members.	Purposive sampling, Snowball sampling	20 informants and three times visit
2	Key Informants	-One family member of caregivers or stroke patients	Purposive sampling	9 key informants and one time visit

Informants are main caregivers in this research who take main caring responsibility of stroke patients within a family. Key informants are one of family members or stroke patients of family caregivers. In this research, key informants who are closure of family caregivers are used as resource people. Key informants are used to help in understanding of the family caregivers’ burdens and beliefs in caring because family caregivers have to communicate and have to ask support or help from them in caring process.

Among twenty cases of the study, the researcher conducted two cases are under a year of chronic cases and about thirteen cases are five years and over five years. In addition, the researcher usually conducted the research at the houses of participants to apply the observation of family relation and communication of family during interviewing process, physical appearance of family caregivers and condition of stroke patients.

On the other hand, if two or more family caregivers have at the same house, the researcher takes the primary caregivers who are more spend time and taking responsibility the stroke patients by bathing, preparing meals, changing the clothes, go with the hospitals for regular check-up. In this study, the researcher did not face any difficulties in choosing participants or family caregivers among the family members because even there were two family caregivers, one of them usually takes care night time and works out during the day time. In addition, the secondary caregivers or one of family members usually take care the stroke patients during the primary caregiver is busy and goes out. Therefore, the primary caregivers who know about the stroke patients well and spend more time with stroke patients were chosen as main participants to get rich information and data in this study.

The key informants were one of family members or relatives who live together with family caregivers. Only nine key informants were recruited in this study because the researcher met family caregivers and stroke patients during interviewing in the daytime. The reason of why the researcher was hard to meet the rest of family members was they went out for work and school during the daytime of interviewing process. Another reason is only stroke patient and family caregivers live in some families. Therefore, the researcher had to consider the stroke patients as key informants. If stroke patients were available to speak, the researcher conducted them for key informant interview. Therefore, among nine key informants interviews in this study, five key informants were one of family members whereas four key informants were stroke patients.

3.2 Research Methods

3.2.1 In-depth interview

To access the beliefs and burdens of family caregivers, in-depth interview is the one way to see the inside mind deeply. The interview is semi-structure interview. The type of interviewing is narrative telling because of accessing the past history, past experiences of caring and future planning. The questions in in-depth interviews guideline show the right way of interviewing. The researcher conducted the interviewing process for three time visits for informants' in-depth interview.

There were twenty participants in the in-depth interview in this study. In the first time visit, the researcher followed with physiotherapists when they visited the patients' houses for physical therapy treatment. They introduced the family caregivers with the researcher. During the physiotherapists giving physical therapy treatment to the stroke patients, the researcher talked with family caregivers such as informal chatting to build rapport with them. After that, the researcher explained the family caregivers to purpose of research well and asked permission to get voluntary participation. Although the family caregivers are usually busy with the tasks of housework and stroke patients, the researcher can do informal chatting to first step of trust building in the first time visit.

Generally, the family caregivers were busy with stroke patients' tasks and housework tasks in the morning and evening. The researcher can do in-depth interview from 1 o' clock to 4 o' clock in the afternoon. So, the researcher could do one interview of one participant per day. Hence, as the family caregivers were busy with patients' tasks and less personal time, three participants denied to conduct the research. In the second time visit, the researcher explained about the research again such as research ethic and rights and purpose of research before starting the actual interviews. After the participants understand about research, the researcher asked the informants the confirmation their voluntary participation with oral consent. And then, the informants were asked the permission to use recording, write down notes taking and take photos before doing interviews. As the researcher did the trust building in the first time visit, the family caregivers act friendly and talk openly during the interview process. The

whole interview process for second time usually takes from an hour to one and half hours.

In the third time visit, normally, the researcher started with informal chatting and then asked the questions to cover the answering the research question fully. In addition, the researcher asked the same questions by changing words, but same meaning of second time visit questions to get validity data.

Hence, one participant from case two was busy with her job and the researcher went her office in the lunch time to conduct interview for second and third time. Furthermore, participant from case ten do not willing to conduct interview at his home because his elderly brother is aggressive type and that elder brother hurt him last year. As he was worry about the security of researcher and the second and third time interviews were carried out in tea shop. Finally, in case 17, 18 and 20, the researcher followed the INO team when they went field work in suburb area of Mandalay. However, the place is far and the researcher could not go there alone again. Therefore, the researcher did just one time interview for these cases.

3.2.2 Key informant interview

The perspective using in this study is family belief system. To explore how the family support affect the burden of family caregivers and to understand roles of family caregivers from family members, key informant interview is used. According to perspective, all the family members involve main roles in shaping the perception and beliefs of family caregivers in taking care of stroke patients. Moreover, another thing of using key informant interview is to get rich and reliable data for study. Key informants interview was conducted with nine participants among twenty cases. Among nine key informants, five are one of family members and four are stroke patients. The researcher could not conduct key informant interview in every case because some families live with only stroke patients and family caregivers and some stroke patients are difficult in speech. In addition, in some families, the researcher did not see any family members during day time because all family members work out or go to school in the day time. Therefore, as the researcher faced difficulties to recruit one of family members for key informant interview, the stroke patients who have little difficulties in speech with little unclear voice involved in the key informants interviews. However, the researcher faced

another difficulty because stroke patients could not talk long and getting data from stroke patients was limited in the study.

3.2.3 Observation

The reason of why the researcher used the non-participant observation was for helping to reduce reactivity, how to ask relevant questions, to understand process of cultural and family contexts of situations. Therefore, under the observation, the researcher observed the communication and interaction among family members. In reality, the researcher faced difficulties to observe the communication of other family members part because some families of participants live only stroke patient and caregiver at home.

3.3 Research Instruments

The researcher used three instruments;

1. In-depth interview guidelines
2. Key informants guidelines
3. Observation guidelines

The guidelines of in-depth interview, key informant and observation were developed by using the conceptual framework. However, the researcher tried informants and key informants to answer the semi-structured questions like a narrative talking because there were lots of past histories accessing in family belief system. Moreover, the researcher also performed as a research instrument because the researcher conducted the whole research process to achieve the research objective goals. In addition, voice recorder and note taking were useful for interviewing process.

3.4 Data Processing and Analysis

The ongoing data analysis and content analysis were used. During the interviewing process, the researcher wrote down as jotted notes what things see and hear. After the interviewing process, each notes expended as sentences before forgetting

what seeing things and hearing cases. In-depth interview or informal interview was expanded every day and concluded at the end of each day. After that, data from voice recorders was transcribed as soon as possible after recording from in-depth-interview day by day or within a week. Before going to second time interview of each participant's house, the researcher read and checked all expended notes and recording again to prevent bias and loss of information. And then all data were translated from Myanmar language to English. After that, the data were categorized according to the contents in theory. The process in the analysis of data was coded by classifying and categorizing individual pieces of data. Then, the researcher wrote memoing for describing and defining concepts, dealing with methodological issues and offering the theoretical formulations. Finally, mapping was done to show concepts and their interrelations.

3.5 Trustworthiness of the Data

To get validity data, in the in-depth interview, the researcher tried to ask the same questions at different times and change the words but same meaning of questions. Moreover, the key informant interview was also used for getting data validity. Finally, the observation was added to get reliable data.

3.5.1 Trust Building

Trust building was very important issue in interviewing process because the reliable and rich data could not get if the participants did not trust the researcher. Before starting the interview, the researcher said greeting the informants and key informants. The researcher introduced the informants and key informants as a master student in Mahidol University and studied at physiotherapy subject in Mandalay. One reason of introduction as physiotherapist was the researcher would like to access the stroke patients' conditions of hygiene and treatment plan. Then, the researcher explained the purpose of study to ask the permission. After getting permission from informants and key informants, the researcher started the informal chatting. After the informants and key informants felt comfortable by chatting with researcher, the interview was

conducted. These processes were done steps by steps by take time. The researcher visited the informants' houses for three times and every time the researcher followed the above process to approach the informants.

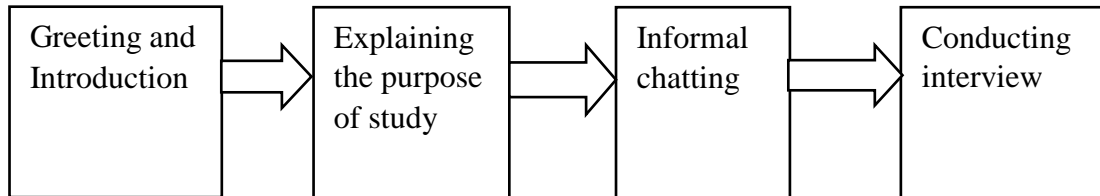


Figure 3.1: Steps of trust building in interviewing process

During these processes, the privacy, confidentiality and informed consent were very important and the researcher explained very clearly the respondents before starting interviews.

3.5.2 Reflexivity, Data and Methodological Triangulation

To get reliable data, the researcher has to understand the role, duty and tasks of researchers. The researcher did not use the past work and academic knowledge like giving advice and comments during interview process. The researcher self has not included from the research process and just need listening to full attention and respect by separating own feelings. As a result, the researcher could not make any bias the interpretation of data by understanding the researcher duty.

In the research field site, as friends and teachers introduced the researcher to informants as physiotherapist and student, some participants asked the researcher about the how to take care of stroke patients, ask about diseases and treatment. The researcher gave a piece of advice and physical therapy treatment after finishing the interview process because the researcher would like to avoid bias from using past academic knowledge and work experience during interviewing process. Moreover, the researcher did not give any judgment the participants and listened to with full of attention and respect during interview. During the doing field work, the researcher observed some practices of caring that is harmful for stroke patients. For example, one participant gave the medicine which is not related with the stroke such as paracetamol and bremerton twice a day to the stroke patient for twenty years. To concern about

reflexivity, the researcher did not give any comments during interviewing process and gave a piece of advice after interview.

Two kinds of data sources from in-depth interview of family caregivers and key informants interview of one of family members or stroke patients helped to improve the validity of data. By comparing the data getting from informants and key informants interviews help to achieve data reliability.

3.6 Ethical Consideration

Ethical concern is an important thing in social science research. This research had been started after receiving the approval from IRB (Institutional Review Board), Mahidol University. Before that, the researcher took IRB Exam and then the result was submitted to the IRB committee of Mahidol University to conduct the research before entering the research site.

3.6.1 Privacy

The researcher needs to respect the privacy of participants. The place of interview must be private place to conduct convenience research. Mostly, the in-depth-interview was conducted in participants' house. If the participants were not convenient at their home, then ask them which place they prefer to interview and they usually chose at tea shops and work office. Not only the place but also time was considered when interviewing process. Almost all of family caregivers were not free at the morning and evening because they were busy with stroke patients' staffs and house work. Therefore, the place and time was decided carefully to encourage feeling comfortable and to share their private perceptions and beliefs deeply and openly. There was no third party try to pass and talk with conversation during interviewing process.

3.6.2 Confidentiality

Confidentiality is the one of main researcher's responsibilities to make clear understanding of respondents. In the study, by protecting respondents' identity, the researcher tried not injuring the respondents anyway. The researcher protected not only their identities but also their given information. Therefore, the participants' names were

used as pseudonyms in this research. All information that received from participants such as recording, field notes, photos, transcription and note books were kept surely to use no one except researcher. Finally, all information and data were deleted after finishing process of data analyzing and report writing.

3.6.3 Informed consent

Social research touches an intrusion into people's lives like unknown things or cases of family members or friends. Moreover, the informants and key informants have to spend significant time and energy for interviewing process and it disturbs the regular activities. The informants and key informants were explained well about making free decision for participation in the research. It must be voluntary participation and any one was not forced to participate such as leaving the involvement of research at any time for any reason. By respecting informed consent, the researcher missed the three family members who denied to conduct the research because they were busy and could not give time the researcher to conduct interviews.

In addition, the identity and contact address of researcher were given to the participants to validate that the researcher was a part of the community and any cases happened could contact the researcher easily. Furthermore, the researcher considered no harm to the informants which means that the participation did not embarrass or endanger the informants such as home life, relationship of family and jobs.

Firstly, the participants were recruited with oral consent and then participants (family caregivers) and key informants (one of family members or stroke patients) were given informed consent paper before conducting interviewing. Hence, as all informants were over 18 years old, there was no need to get permission of family caregivers' guardians. Then, after agreement from the participants, the researcher asked permission to do tape recording, writing field note and taking photos in the interviewing step.

3.6.4 Benefit and Reciprocity

The family caregivers were provided the small gifts such as foods and towels to compensate the time sharing of their caring experience and beliefs of caregiving and to appreciate the efforts of caregiving role after interviews. In addition,

the researcher shared caring information when the participants asked some questions about caring of stroke patients because the researcher worked as physical therapist. Moreover, as some stroke patients feel arm and shoulder pains, the researcher gave the physiotherapy treatment after interviewing the research.

Furthermore, health policy makers and health care professions are easy to set up health care policy especially for stroke patients and family caregivers by looking at the findings and evidences of this research and provided recommendations for family level, community level or government level. To sum up, the findings and evidences can assist the family caregivers and stroke patients in taking caring role of family at home because this research helps to guide the health care policy makers to improve the quality of life of stroke patients and family caregiver.

CHAPTER IV

RESEARCH FINDINGS

The whole things of this chapter can be imagined by understanding general social context of Mandalay, general social context of family, characteristics of informants, characteristics of key informants, characteristics of stroke patients and family history. In addition, family system answers how the families and caregivers make role management in caring of stroke patients. Moreover, family caregivers expressed their perception based on family belief system in taking caring roles and stroke disease while they are facing burdens in caring of stroke patients at home. Finally, coping way strategies show to answer how the family caregivers cope with the burdens.

4.1 Overview of Mandalay in Myanmar

Mandalay is the second largest city in Myanmar and located in central dry zone of Myanmar. It was built on the foot of Mandalay Hill as a new royal capital by King Mindon in 1857, named as Yadanarbon (city of Gems). It was the last royal capital of the Konbaung Dynasty. It was former capital city of Myanmar before British exile the last King Thibaw and his queen to India in 1885. The palace surrounded by moat and many pagodas around the Mandalay city are famous for the ancient architectural heritage places in Myanmar.

4.1.1 Demographic profile of Mandalay City

Mandalay city is situated in center of Myanmar. It was built on the east bank of Ayeyarwady River which flows from northern part to southern part of Myanmar and it is the most important river in Myanmar. This river is the main flowing goods by water transportation mode such as teak, bamboo, oil, rice and beans in Myanmar. The city is built based on the square moat of palace and divided by seven townships which are Amarapura, Aungmyethazan, Chanayethazan, Chan Mya Tazi, Maha Aung Myae,

Pathein Gyi and Pyi Gyi Dagon. Each township has famous landmarks of Mandalay or specific different physical features. So, types of jobs are different based on these.

Mandalay Hill, moat and palace and famous ancient pagodas on the foot of Mandalay Hill are situated in Aungmyethazan Township which is called one of tourist attraction places in Mandalay. Among seven townships, Chanayethazan is city center and main business township because places are always crowded with people in supermarkets, shopping plaza, schools and hospitals. In Chan Mya Tazi Township, Mahamuni Buddha Image which is famous temple in Mandalay and people living around the temple do their living related with religion such as making marble and bronze Buddha image, temple ornaments and paraphernalia and working of gold and silver leaves to decorate pagodas. Mandalay Industrial Zone is situated in Pyi Gyi Dagon. Most area of Maha Aung Myae is residential places and some people living in this township work as jade cutting and selling. As Mandalay become urban sprawl, the two townships of Amarapura and Pathein Gyi add as Mandalay District. Most area of Pathein Gyi is covered with paddy fields. Amarapura Township is famous for traditional silk and cotton weaving.

4.1.2 Economic Status

To compare with other towns in upper Myanmar, economic status is better because Mandalay is a hub by connection lower Myanmar, upper Myanmar, China and India. As the trading business is good between China and Myanmar, almost all products consumed in Mandalay like clothes, electronic gadgets, foods and motorcycles are imported from China. Generally, agricultural sector such as growing rice, wheat, peanut and vegetables and traditional industries sector such as silk weaving, stone and wood carving and jade cutting improved in Mandalay.

In addition, people work as dealers and sellers in general because Mandalay is a center of trading and exchanging goods in upper Myanmar. As there are lots of supermarkets and plaza in the city center, people work as wholesalers of other towns such as clothes and electronic gadgets. Moreover, people who living in countryside work mainly as farming by growing vegetables, mangoes and limes. As Mandalay is situated at river bank, some people around river work as trading goods such as rice and oil.

Overall, the socioeconomic status of people who are living in city center is better than people in countryside.

On the other hand, small shops, marts and grocery stores are scattered in the residential place of both city center and countryside and they are seen as a small family business. In this study, family caregivers need to take care of the stroke patients at home for long time and most of them find the jobs that can do at home by caring of stroke patients. As a result, some family caregivers work at small shops or grocery stores at home. Furthermore, some caregivers who live in countryside do farming at home yards and care the stroke patient at the same time.



Figure 4.1 Grocery Store at home in Mandalay



Figure 4.2 One participant's grocery stores at home

4.1.3 Educational Status

Today education system is improved a lot by establishing many public and private schools in Mandalay. However, due to limited number of schools, limited family financial status and less knowledge about education of adult family, people especially from countryside did not get proper education in the past. Less knowledge about education of adult family means parents allowed their children especially girls to attend the school till the end of primary education level. Adult family members perceive that girls need to attend school till they can read or write for emergency cases. After that, girls have to out the school and they have to do housework or look after the younger brothers and sisters at home. In addition, children from poor socioeconomic status family are not interested in study and they try to work out for living by quitting the school before high school level.

This study of family caregivers and other family members experience similar situation. Among participants in this study, mostly, female middle aged family caregivers stopped their education before high school level because of less knowledge about education of adult family. Moreover, in one participant's family, four children quit the school because of poor family socioeconomic status. Due to poor socioeconomic status and suffering of stroke by father or breadwinner, children are not interested to study and they try to work out for living.

4.1.4 Healthcare and its accessibility

People can access health care from public sector, private sector and non-government organizational sector. Private hospitals are generally good services whereas the cost of treatment is expensive. The cost of treatment in public hospitals is cheaper than private hospitals. But, health care service is poor because public hospitals are always crowded, waiting for long time and shortage of medical professions and staffs. People from high socioeconomic status prefer to take treatment in private hospitals whereas people from low socioeconomic status prefer public hospitals. Health care professions from non-government organization give treatment home based in community. However, they can visit once per month at home and patients who need regular care and treatment cannot utilize this health care support.

For stroke cases, stroke patients need to go to hospitals for treatment in both private and public hospitals. Basically, as stroke patients have difficulties in moving, family caregivers encounter a problem to carry the stroke patient to hospital for treatment and medical check-up regularly. So, they choose traditional medicines and massages at home for long term. The cost of treatment of traditional medicines and massages is also not cheap since the stroke patients can take treatment at home. In practically, stroke patients in the study receive traditional massages and medicines at home from the beginning of suffering stroke till about one to five years. After that, they do not receive traditional massages at home from traditional medical practitioners because the nature of stroke is long term chronic disable disease and treatment is not effective to walk or move for stroke patients.

Moreover, stroke patients face difficult to access health care services because Mandalay has poor public transportation system. People cannot hire taxi easily and cannot use public transportation easily. When stroke patients need to go to hospitals for treatment or medical check-up, the family caregivers face difficulties to take the patients to hospitals. Therefore, doctors or traditional medicine practitioners visit stroke patients' houses for treatment. In addition, the expensive cost of transportation adds a barrier of going to hospitals. As a result, the stroke patients do not get regular check-up or treatment.

On the other hand, stroke patients need treatment continuously to control blood pressure and other diseases such as diabetes and heart diseases although they feel

well at home. By looking at the study sample, some families from good socioeconomic situation can give regular medication and treatment including physical therapy for the stroke patients. They try to take the patients to see doctors once per three or six months and some try the doctors to visit at home for treatment. However, some family caregivers think that the complication of stroke is high blood pressure and stroke patients need to control blood pressure. Stroke patients from these families receive regular medication to control the high blood pressure. Some stroke patients do not receive regular medication and treatment because families are from poor economic situation and some think that stroke patients cannot get recovery and treatment is not effective.

4.1.5 Religion

Most people in Myanmar are Buddhism and they follow the Buddha principle. According to Buddha principle, every person experiences suffering such as old, pain due to disease or old and finally death. People suffer pain in old age when individual's body begins to degenerate or suffers some kinds of diseases. As all people have to pass the aging time, young people must treat the elderly, particularly parents, with the suitable respect. So, young Buddhists have an obligation to respect and help the elderly by giving compassion for the suffering of elderly people. In addition, parents sacrifice for children by giving their time, money, energy and pain especially mothers who experience it while carrying the baby in the womb for nine months and then give birth. Therefore, children must have filial piety by caring when parents are old and need the help of young children. In Buddha speech, paying the debt of parents is the main thing of teaching.

Buddhists also believe deeply in 'karma' and they can escape suffering when they attain heaven or nirvana- the ultimate state of blessedness. Due to lives of people circulate between birth and death again and again or reincarnation, past life action reflects good or bad things of present life. Good actions contribute good karma and future happiness; however, bad actions done by intentionally contribute bad karma and future suffering. Buddhists refrain doing bad things or bad actions to get good karma in the future time or future life.

During data collection period, the whole things of family beliefs in caring are related with karma issues. Taking caring roles of stroke patients make suffering such

as financial difficulties, social isolation, physical and emotional burdens the family caregivers. Family caregivers think that they did the bad things to stroke patients in the past life and they have to repay back those bad things in the present life. Although they think that they have burdens in caring of stroke patients for long time, they take care the patients well with full of attention and effort by giving the best care to get good karma or merit in the future life or time. If they do not care of the patients well such as yelling the patients with impatience voice during doing their daily tasks, it will lead to bad karma or demerit or going to the hell. Furthermore, caregivers also believe that caring of stroke parents is repaying the debt of parents. Finally, Buddhists believe that modesty such as caring by someone of opposite sex is improper action. The family caregivers who take care of the opposite sex of stroke patients are sensitive in bathing and cleaning of sex organ after toileting.

4.1.6 Overview of family and community

In this study, concept of family such as family structure, meaning and value participate the most important role to understand the family beliefs of caregivers.

4.1.6.1 Family meaning and type

A family is the smallest social unit in the society. Family is a group of people and family members live together by sharing their money and food and taking care of each other. Family members are either brothers or sisters of genetically related or husband or wife of legal bond. By comparing family life and public life, family life is private and intimate.

Traditionally, elderly care has been responsibility of family member and provided within the extended family. In Mandalay, taking care of elderly is not difficult in the past because almost all family types are extended families and there are lots of family members who can take caring roles in family. Family caregivers from extended families receive help in caring and financial support from other family members. However, nowadays, as lots of nuclear families are occurred in Mandalay, taking caring responsibility of stroke patients is difficult for nuclear family. In nuclear family type, family caregivers receive less or lack support from other family members in caring process because of less number of people who can take caring role in family. So, family caregivers take many roles such as caring, doing housework and working at

the same time. In addition, most of stroke patients in this study are elderly. Those decreasing family size and greater life expectancy of elderly people are main problems of caring the stroke patients at home.

4.1.6.2 Family structure and function

The structure of family in Myanmar is different from western culture. It is true that children leave the parents' house and stand independently by own foot when they are adult in western culture. Older parents also prefer living independently and individualism (Spitzer et.al., 2003). However, adult children in Myanmar live with parents and take care of the parents when they are sick or elder.

Normally, a family in Myanmar is composed of grandparents, parents, children, uncles, aunties, nieces and nephews. Father or the eldest family member or a person who can earn money the most is the leader of a family. Family leader is the most prominent breadwinner who contributes a significant portion of family finances. In one hand, father roles or duties include providing financial support and making critical decisions and the rest of family members obey the decision of father. On the other hand, for mother roles or duties in family, family income flows to mother who manage to meet the needs of all family members at home. Typically, family members seek mother's advice and permission in regards to any decision concern with household and caring such as caring elderly and children rearing. In fact, father stands as leader, breadwinner, provider and spokesperson of the family when mother takes maker of home and main nurturer of children. Therefore, father is the power, mother is the minister and children are followers at home within a family.

The obvious thing of taking roles in family is men take productive role and women take reproductive role. Among women, middle aged women take usually reproductive role in families. Normally, when husband works out for family, wife has to manage the whole family such as family financial and social things at home. These women not only take doing housework and caring responsibility but also try to nurture the children well. These women teach the children elder people are respectful and younger ones have to take care of the elder people with or without feeling sickness. Thus, they take childbearing, domestic work and caring elder people in family while some are working out.

There are reasons why the middle aged women especially wives do many roles in family because of family expectation on them and own expectation on family. They take caring, domestic, childrearing and working roles in a family because of family's expectation of mother as ideal image mother. Even though they are full of experience by passing and learning of difficulties in young age, they are mature physically and mentally in a family. Therefore, family members think that they can solve problems easily and can stand difficulties in a family. As a result, they play pivot role or center point in the family because they are the main internal mediators by taking lots of roles to handle the family needs or problems. On the other hand, mother's expectation of family adds them to take many roles in a family. They expect family as happy and peaceful family by protecting other family members not to be tiredness or family separation. As they do not want to be family broken, they are absorber of family sadness and tiredness within a family.

In the past, wife did not need to work out and only earning of husband was enough for family. However, lifestyles in Myanmar have been changed and married women have to work out to earn enough money for family living. At the same time, they have to do housework and look after the kids. If one family member feels sick, married woman has to take main caring role in family. Two married participants who take care of their stroke husbands reflect the married women life in Myanmar. They said that

"I do not feel I have to do more after stroke because I have to do all his tasks including cutting nail and shaving beard and moustaches before stroke. When I cook fish, I have to prepare his meal by removing all fish bones. I have to do one more task after stroke. It is helping him toileting. I used to all his tasks before stroke."

"There is no difference before and after stroke. My husband gives me earning money after he comes back from job. But, he is not interested that money is enough or not for our living. He thinks that he does his duty after giving money me. His money is not enough for our family living. So, I have to work out to be enough our living. After I am back from my work, I have to do house work too."

Family system is flexible and adaptive to type of family and family economical conditions. In this study, when the family experiences the caring of

stroke patient by one caregiver, they make role changing within a family. Although roles and duties are fixed in a family between males and females, male family members also take caring role of stroke patients according to family needs. In addition, female caregivers add the caring role to previous roles of doing housework and childbearing roles in family. Therefore, to balance the family structure and function, roles of family change according to requirements or needs of each family member.

4.1.6.3 Family value

Family is one unit like combining mind and body as single one. Family is essence of love and connects idea of spirit word and physical word. A family is the ethical foundation and primary organization. In such a family, love becomes the standard of value. The family value transmitted within the family by passing from generation to generation. As the family bond as solely unit, all family members share their happiness and sadness each other by filling one's needs to another. So, family can help each other whatever, whenever, wherever and however under unconditional things because family was built with love, understanding, sympathy, honesty, loyalty and faith.

The ideal family is eternal love of each family member and love is accomplished all family tasks or things in a family. If a parent is sick, the child will do whatever is necessary to cure the sickness even to the extent of selling of the family's properties because of bond of love and sacrifice for one another. A son or daughter cannot play a perfect role of son or daughter without love. Hence, elder siblings are to sacrifice themselves by representing parents in loving younger ones. These order and traditional love come from attachment and filial piety in family. Their feeling is same because they are one unit. If one family member feels sad or painful or worried, others feel like that. In other way, if one family member is happy, others also feel happy.

By looking at the family caregivers and the rest of family member who take care the stroke patients for long time, caring is based on filial piety and attachment such as love. As the family shares sadness and happiness together, the family caregivers feel painful or sad when seeing the painful or disability of stroke patients for long time. In addition, family caregivers prefer the stroke patients caring by family members because stroke patients can receive warm, love and kind from the family caregivers.

4.1.6.4 Family moral value

Every family from different religions, different ethnicity or different places has own moral values. Like other families in the world, all families in Mandalay covering other areas of Myanmar have specific family moral values. Mainly, ancestors and religion set up the moral things for younger generations and grandparents or parents teach the younger ones especially their children at home. Mostly, mothers or grandmothers take that role because they perform the nurture role of children at home. In addition, they do and follow the moral things to be ideal persons within family.

The obvious moral thing of Myanmar is respect and seniority. Younger people pay respects the elder ones such as parents or grandparents because elder people are knowledgeable and wisdom persons. They had full of experience by learning from the past and younger people ask a piece of advice from them by listening to their past experience. Therefore, as they are respectful and seniority people, the younger ones do not try to say rude words such as saying bad languages and shouting loudly. Within family level, grandparents and parents are respectful family members and younger family members do not try to act or say less respect things at home.

In Myanmar, that respect and seniority culture also includes in relationship between elder brothers or sisters with younger ones. The elder brothers or sisters have to look after the younger ones to help the parents at home. In addition, the elder sisters represent at home as behalf of mother and they have to perform the some tasks instead of mother such as caring of younger siblings and doing housework. Same as elder sisters, elder brothers stand at home as behalf of father and they have to perform some tasks instead of father. Thus, in Myanmar family culture, elder sisters and brothers take more responsibility at home and younger ones pay respect the elder ones and they have to follow the advice and saying of elder ones.

Since a person involves as a member of a family, family duty or responsibility reach on the shoulder of that family member automatically. Fathers do their responsible father duties of supporting family financial and mothers do house works and nurturing of children to fill their duties. In fact, everyone in family has to fill their duties one needs to another. In that sense, as parents sacrifice their energy, time and money with unconditional love to their children, children have to pay it back when they are older or sick. In addition, for marriage couples, both of them make bond to

share sadness and happiness whether poor or rich and healthy or unhealthy within family. Therefore, paying the debt of parents and marriage commitments are basic moral values within a family.

These kinds of respect, seniority reflect in caring of stroke patients in this study because family caregivers treat and take care the elderly stroke patients with full of respect. Moreover, family caregivers believe that caring is family duty, repay the debt of parents and married commitment that descends from family culture. They do not try to abandon the stroke patients even they suffer some kinds of burdens and difficulties in caring for long time.

4.1.6.5 Involvement of friends, relatives and neighbors in family

Although Mandalay is a big city in Myanmar, the close-knit community still exists in many places in Mandalay. Mostly, neighbors know each other and help each other in social events such as wedding, religious ceremonies or funeral. In this study, if one neighbor feels sick and hospitalized, they usually go to hospital with snacks or money to soothe the patients and family members. Some neighbors help to take care the patients in hospital if families have shortage family members for caring. Moreover, family caregivers can receive health care knowledge for caring of stroke patients from neighbors who experience past stroke caring.

Oftentimes, families have to provide elderly care and prefer the traditional methods of being cared by younger generations of family members. In Myanmar traditional, families try to provide elderly care at home and families. People around the environment or in community think that the concept of nursing home to provide elderly care is considered culturally unacceptable. Furthermore, people from environment like neighbors, friends or relatives blame or try to saying sarcasm if the family do not care the stroke patients or leave them without taking responsibility.

4.2 Characteristics of Informants

Among twenty informants, Kyi, Tun, Naing and Soe are male and the rest of sixteen participants are female. Interviews are carried out with nine daughters, five wives, two sisters, three husbands and one son. In this study, female caregivers are four

times larger than males and female caregivers occupy mainly the caregiving role in family. It is obvious that female occupy household or internal or reproductive role in a family although participants are randomly selected.

Ages of participants are one is 20s, three are 30s, eight are 40s, four are 50s, three are 60s and one is 70s. There is not much losing of labour force in family because mostly caregivers are not young age. In addition, middle aged women take mainly caregiving role in family. Twelve out of twenty participants are married; six are single, one divorced and one widow. As the number of married caregivers is much than single, they have to perform lots of tasks such as caring, working, doing housework, looking after kids and doing husbands or wife tasks at the same time.

Only one participant of Khin works full time job. She can work full time because she can hire day and night special nurse to take care of her mother at home. Four participants work out as part time job such as buyer of shop, two hawkers and broker. They need three to five hours to work out in the morning or in the evening. Others like helper of home shop, seller of fuels, investor of rice and beans, fortune teller and planter work at home. The rest of eight are jobless including one retired participant. Whereas one caregiver's full time job is skillful and well-paid job, the rest of caregivers do not include in professional or well-paid jobs. Therefore, economic status of family caregivers is poor because most of them are jobless and low-paid jobs. For example, the daily earning of hawker is between 2000 kyats and 5000 kyats. (1\$= 1300 kyats in March, 2016).

Participants' education levels are one illiterate, three primary education, three middle school, six high school, six graduated and one master. By looking at their education profile, family caregivers are poor not only in economic status but also in educational level. Thus, most of them work as unskillful jobs due to their low education level. To compare with other family members, they stand in low education and economic status in family. These are one main causes of why family caregivers take primary caregiving role in family. The religion of Myanmar is mainly Buddhism and almost all participants are Buddhism except Khin, is Christianity. The relationships with patients are three husbands, three wives, eight mothers, two fathers and two sisters.

In case one, family type is nuclear type. The caregiver is middle aged married woman. She lives with stroke husband and two young sons. As the husband

suffered stroke for eight months, she is a breadwinner of the family. So, she has to perform a lot of tasks such as working, doing house work, caring husband and rearing two kids. She can work out because stroke patient can walk with sticks and can do daily activities with little assistance. But, family financial is not stable because husband who is the main family financial provider suffers stroke.

In case two, family type is extended type. The caregiver is middle aged married woman who takes care of stroke mother for eleven years. She lives with a young daughter, a sister-in-law while the husband is working out other town. She hires special nurse to take care stroke mother day and night as she works out and stroke patient is bedridden. So, she takes four roles such as working, domestic work, caring and childbearing. The caregiver does not feel worried about the cost of treatment because it is her mother's money.

In case three, family type is extended type; but, less family size or number. The caregiver is old aged single woman who takes care of her single elder sister for twelve years. She lives with stroke elder sister, married younger brother and sister-in-law. As she quitted the job to take care of patient, she needs to perform two roles such as caring and doing house work now. She is facing difficulties in caring because of old age and suffering hypertension. In addition, bedridden patient and without getting help in caring from other family members add more difficulties in caring.

In case four, family type is nuclear type. The caregiver is single middle aged woman who takes care of old stroke mother for five years by living with seven single siblings together. Not only she takes caring and doing housework but also she helps in one of her sister's shop at home. However, she does not need worry about caring and family financial because the rest of siblings share caring role and support money in family. In addition, stroke mother can do daily activities with little assistance in walking and bathing from hers.

In case five, family type is nuclear family. The retired old man who suffers asthma and hypertension takes care of stroke wife for five years. He lives with a single son and stroke wife at home. So, he has to perform caring and doing house work at home while son works out at the day time. He is facing lots of difficulties in caring because he is old with suffering some kind of diseases and stroke wife needs lots of assistance from him in daily activities. However, son helps in caring and doing house work a lot.

In case six, family type is extended family. The caregiver is single middle aged woman who takes care of the single elder sister for three years. She lives with stroke sister, married elder brother and his family. She does not need to work out and she needs to take caring and doing house work at home. As she is fat and suffering hypertension and stroke patient depends on her all daily activities, she is facing difficulties in caring. She does not need to worry about family financial including treatment cost of stroke sister because elder brother supports these.

In case seven, family type is nuclear family. The caregiver is single middle aged woman who takes care of stroke mother for a year. Caregiver lives with stroke mother and she is the main financial provider in family. So, after stroke, caregiver moved to her fuel shop to do caring and working at the same time. The caregiver does not need to worry about in caring and doing housework because stroke mother can do daily activities herself by walking with stick and housemaid does domestic work at home.

In case eight, family type is extended family. The caregiver is old man who takes care of his stroke wife for nine years. He has big family and living with one married daughter and her family, one single daughter and one niece. He changed his career to take care of his wife and helps his daughter's shop at home. Although he changed his career, family does not need to worry about stroke patient's treatment cost because all adult family members have regular earning money to support family. In addition, he does not face difficulties in caring of bedridden stroke wife because his single daughter and niece help a lot in caring role.

In case nine, family type is extended family. The caregiver is single young woman who takes care of her stroke mother for six years. She lives with stroke mother, one single elder brother, one married elder brother and his family. As stroke mother needs much assistance from her, she stays at home for caring and doing house work without going out for working. She receives support in caring and financial from single elder brother.

In case ten, family type is nuclear type. The caregiver is single young man who takes care of his stroke mother for five years. He lives with stroke mother and one elder single brother together. He experiences tiredness in caring because there is no one who can substitute in caring role and stroke patient needs much assistance from him for

daily activities. Caring is only his task and he does not need to worry about cost of treatment because stroke mother has saving for the treatment and living cost.

In case eleven, family is nuclear type family. The caregiver is married middle aged woman who takes care of stroke husband for a year. Caregiver lives with only stroke patient and her son supports money by working at other town. When the breadwinner of family suffers stroke, caregiver does not have job. So, caregiver sells a car and invests in her uncle's business to get regular earning money. In addition, the caregiver does not experience difficulties in caring because stroke husband can walk and husband's family support money for treatment.

In case twelve, family is nuclear type. The caregiver is middle aged woman who takes care of stroke mother for five year. Caregiver is only daughter and lives with stroke mother together. As one of her cousin brother supports money for living, she needs to perform caring and doing house work without working out. However, she is facing difficulties in caring because no one cannot share caring and domestic tasks, stroke patient depends on her almost all daily activities and she suffers kidney stone disease herself.

In case thirteen, family type is extended type. The caregiver is middle aged married woman who takes care of stroke husband for six year. She lives with stroke husband and a young school daughter and also lives with husband's siblings separate houses in the same yard. As the breadwinner of family suffers stroke, caregiver takes working, caring, doing housework and childrearing at the same time. When the husband suffers stroke, caregiver stopped working and family experiences financial difficulties in living and treatment cost.

In case fourteen, family is extended family. The caregiver is middle aged married woman who takes care of bedridden stroke mother for a year. She lives with stroke mother, single elder sister, sister-in-law, one nephew, her husband and a young daughter. As she has to perform four roles such as caring, doing housework, working and childbearing, she is facing difficulties to do all roles at the same time. But, the eldest and the youngest married brothers support the treatment cost.

In case fifteen, family is also extended type because caregiver lives with stroke husband, one single son, one young daughter, one married daughter and her family. The caregiver is middle aged married woman who takes care of bedridden stroke

husband for ten years. She takes caring and doing housework roles without working out because single son supports family living. Caregiver feels tiredness because anyone cannot help in caring and doing housework tasks and they all go out for work and school.

In case sixteen, family is nuclear family type. The caregiver is middle aged woman who takes care of bedridden stroke mother for five years. She lives with stroke mother and two young sons and divorced with husband after stroke. Therefore, she takes caring, working and childrearing roles. She feels tiredness especially emotion because of caring of stroke mother and full time caring leading to divorced.

In case seventeen, family type is nuclear type. The caregiver is middle aged married woman who takes care of stroke husband for two and half years. Caregiver lives with stroke husband in the mango farm of husband's aunty because house is sold for the treatment cost. The caregiver is facing difficulties in caring because she also suffered partial stroke and any one including two sons cannot share caring tasks and treatment cost. The married two sons live separate towns and their financial situation is also difficult to support money.

In case eighteen, family is nuclear type. The caregiver is old aged married man who takes care of stroke wife for six years. As married son lives separately, caregiver and stroke wife live together at home. He is facing difficulties in caring because there is no one who can share caring role and cost of treatment. When wife suffers stroke, he stopped his farming job to take care of the wife which leads debt for him. In addition, he cannot give enough time for his farming due to give more time in caring and doing housework.

In case nineteen, family is extended type. The caregiver is married middle aged woman who takes care of bedridden stroke father for twenty years. She lives with six kids, parents and husband in the upstairs and elder married brother and his family in downstairs. To compare with the number of family, the house is very small. The caregiver feels tiredness in caring because anyone in family cannot share caring tasks and mother who suffers cataract with blind both eyes also need her care. In addition, the cataract mother cannot do eye operation because there is no money to do it in family.

In case twenty, family is extended type. The caregiver is middle aged married woman who takes care of stroke father for seven months and takes care of elder mother too. She lives with stroke father, mother, husband, two sons and young one

niece. The caregiver feels tiredness because she has to do caring of both parents and doing housework roles alone. Husband owns big farming and family financial condition is stable.

Table 4.1: Characteristics of informants

no	Name	Age / Sex	Marital status	Occupation	Education	Religious	Relation with stroke patients
1	That	40/ F	Married	Buyer of shop	10 th	Buddhism	Husband
2	Khin	47/ F	Married	Scholarship advisor	Master	Christianity	Mother
3	Than	60/ F	Single	Jobless	Graduated	Buddhism	Sister
4	Myo	47/ F	Single	Helper of home shop	Graduated	Buddhism	Mother
5	Kyi	73/ M	Married	Retired	10 th	Buddhism	Wife
6	Toe	56/ F	Single	Jobless	7 th	Buddhism	Sister
7	Pa	37/ F	Single	Seller of fuels	10 th	Buddhism	Mother
8	Tun	65/ M	Married	Helper of home shop	8 th	Buddhism	Wife
9	Mon	24/ F	Single	Jobless	Graduated	Buddhism	Mother
10	Naing	35/ M	Single	Investor of rice, beans	Graduated	Buddhism	Mother
11	Yin	55/ F	Married	Jobless	8 th	Buddhism	Husband

no	Name	Age / Sex	Marital status	Occupation	Education	Religious	Relation with stroke patient
12	Name Maw	46/ F	Widow	Jobless	10 th	Buddhism	Mother
13	Htay	46/ F	Married	Hawker- vegetables	Illiterate	Buddhism	Husband
14	Tin	40 / F	Married	Fortune teller	Graduated	Buddhism	Mother
15	Win	50/ F	Married	Jobless	10 th	Buddhism	Husband
16	Khaing	35/ F	Divorce	Broker	Graduated	Buddhism	Mother
17	Cho	51/ F	Married	Hawker- snacks	4 th	Buddhism	Husband
18	Soe	61/ M	Married	Planter	4 th	Buddhism	Wife
19	Aye	42/ F	Married	Jobless	4 th	Buddhism	Father
20	Myint	45/ F	Married	Planter	9 th	Buddhism	Father

F-female, M-male

4.3 Characteristics of Key Informants

There are nine key informants; five are family members of informants and the rest of four are stroke patients. Mostly, other family members work out in the day time of interview. Therefore, only five family members under key informants can be recruited in the study. As four stroke patients can speak clearly, they are involved in key informants. All key informants are female except stroke patient from Cho case. By looking at this data, secondary caregivers of stroke patients are also all female and

female caregivers usually occupy primary and secondary caregiving roles. All key informants are above 40s except 27 years old of Su from Tun case.

Three single and six married key informants include in this study. Among four stroke key informants, three from Myo, Mon and Cho cases had jobs and only one from Soe case is dependent. For occupation of family members, key informant from Khin case works full time job, two from cases of Kyi and Mon work at home and one is dependent. Not only primary caregivers but also secondary caregivers are not full time skillful workers because they also take caring role too. However, one family member; from Aye case worked as massager, stopped working because she suffer cataracts both eyes and need to do operation.

Key informants from cases of Khin and Tun are graduated and two from Myo and Tin cases are high school education level, however, the rest of them cannot be accessed their education level. The relation with stroke patients and participants are two wives, one husband and one mother. The relationship with family members and participants are two elder sisters, two younger sisters and one mother.

Table 4.2: Characteristics of key informants

no	Case	Name	Age/ Sex	Marital status	Occupation	Education	Relation with participant
1	Khin	Mu	44/F	Married	Director- University Christian Fellowship	Graduated	Younger sister
2	Myo	Swe	48/F	Single	Shopkeeper at home	10 th	4 th sister
3	Kyi	Stroke patient	70/F	Married	Seller of snacks in school	-	Wife
4	Tun	Su	27/F	Single	Shopkeeper at home	Graduated	Youngest daughter

No	Case	Name	Age/ Sex	Marital status	Occupation	Education	Relation with participant
5	Mon	Stroke patient	60/ F	Married	Seller of traditional snacks	-	Mother
6	Tin	War	52/F	Single	Dependent	10 th	Elder sister
7	Cho	Stroke patient	61/ M	Married	Shopkeeper	-	Husband
8	Soe	Stroke patient	71/F	Married	Dependent	-	Wife
9	Aye	Nyut	82/F	Married	Massager	-	Mother

F-female, M-male

4.4 Characteristics of Stroke Patients

Ages of stroke patients are two are 40s, three are 50s, seven are 60s, six are 70s and two are 80s. Majority of stroke patients are elderly or retired aged because fifteen out of twenty are over 60 years old. The affected stroke patients are not working aged now. Therefore, they need much support from family or government for their living and treatment cost.

Among stroke patients, five stroke patients, cases from That, Yin, Htay, Win and Aye, are breadwinner of their families. When husbands suffer stroke, family members experience more difficulties especially financial part because husbands occupy main financial providers of a family. As seven stroke patients are dependent or housewife of family, they did not work for family earning and they just do house work before suffering the stroke. Therefore, for those stroke families, there are not much difference in financial part between before and after stroke. However, if the stroke patients take doing house work role, that family faces difficulties in manage of internal

household job within a family. The rest of stroke patients have regular earning money because three are retired and five stroke patients work out as full time and part time before getting stroke.

Stroke patient's illness time is from 7 months to 20 years. According to illness time, family members need to pass three stages; initial, chronic and terminal stage of illness. Four stroke cases of one year illness, cases of That, Pa, Yin and Myint, are initial stage and caregivers and family members have to need still adjustment in caring after getting stroke. Family caregivers from Khin, Tun, Khaing and Aye cases face terminal stage or health condition of stroke patients is not well. So, family caregivers need to prepare separation. They feel sad and some are crying during interview because they are looking at the stroke patients suffering. The illness time of above four cases is long which have 9, 11 and 20 years except 5 years from Khaing case. The rest of cases experience chronic phase and caregivers need to do same tasks and same things day to day.

As stroke patients need the family caregivers to assist their daily activities, degree of assistance is divided into three parts which are bedridden, much assistance and not much assistance. The bedridden patients totally depend on the family caregivers all their daily activities including rolling and turning in bed. Some patients need much assistance from the family caregivers. They can do eating and sitting by self, toileting and bathing with little assistance, but, cannot do standing and walking. Not much need assistance patients can walk and stand with stick. They need a little help in bathing or changing clothes from family caregivers. In this study, six cases from Khin, Tun, Tin, Win, Khaing and Aye are bedridden patients. Whereas stroke patients from cases of Than, Kyi, Toe, Mon, Naing and Maw include in need much assistance, the rest of eight cases are in not much assistance.

As a result, the family caregivers who take care of bedridden stroke patients need to do all daily tasks of patients day and night. They feel more burnout because stroke patients depend on them all daily tasks all time. In addition, if there is no one to share family caregivers' caring tasks, they may feel more burnout than others. Furthermore, stroke includes in uncertainty of nature of disease and any one cannot say exactly when will stroke patients suffer disease again or when will they die. In this study,

stroke patient from Myo case who does not need that much assistance of caregivers passed away suddenly after a month of interview of thesis.

Stroke patients can take treatment in public hospitals, private hospitals, general clinics or neurological specialist clinics and traditional medicine hospital. Among public hospitals in Mandalay, mostly stroke patients can take treatment in Mandalay General Hospital and 300 Beds Hospital for stroke cases. For private hospitals, the patients take treatment in Nyein and Mandalar private hospitals in Mandalay. Government service doctors especially neurological specialists work in private hospital as part time, out of the government service time. These neurological specialists also run their own clinic outside. Therefore, stroke patients take treatment from same neurological specialists with different public or private hospitals or clinics.

Beside neurological clinics, the stroke patients can take treatment in general clinics. General practitioners run their clinics and every ward has lots of general clinics in Mandalay. The treatment cost for stroke cases in general clinics is much cheaper than public hospitals, private hospitals and neurological specialist clinics. Stroke patients from poor family financial status take treatment from general clinics because family can take care of stroke patient at home.

In this study, traditional massage means stroke patients take massage from traditional medicine practitioners or massagers. Almost all of stroke patients take traditional massages at home for long time. Family caregivers hope that stroke patients can move and can walk by doing massages. Moreover, stroke patients get traditional medicines from traditional medicine practitioners or family caregivers bought it from drug stores by themselves.

TLMI (The Leprosy Mission International, Mandalay, Myanmar) is a non-government organization. That organization takes care mainly health of leprosy patients and also take care disable people. This organization supports the stroke patients money, physiotherapy treatment and health care aids such as walking sticks or toileting chair. There are five stroke patients and get support from this organization. People from this organization visit once per month the houses of stroke patients and give physiotherapy treatment. In addition, they support money to build a house of Cho case. Therefore, each family utilizes the different health care services depending upon their family condition such as financial status and number of family number.

By accessing where the stroke patients take treatment in the past and present time, the difference of family financial status and caring of stroke patients among twenty cases are obvious. Each stroke patient receives different caring from their family members according to the family financial status. The stroke patients from high socioeconomic status mostly took treatment of stroke in private clinics about a month. However, stroke patients from poor family financial status receive treatment from general clinics and traditional massage at home. Hence, some stroke patients did not admitted hospitals to take treatment of stroke because of limited family number and limited family financial condition. Toe and Htay said that

“Sister did not admitted hospital because all family go out for work and anyone cannot help to do my housework and cannot help me if she admitted hospital. She took treatment from clinic near my home and traditional massage.”

“Doctor from clinic refer husband to admit hospital. But, I did not take him to hospital. If I take him hospital, I am in trouble because there are a group of pigs at home. He take treatment in clinic and traditional methods at home.”

Moreover, for the present treatment plan, five stroke patients, from cases of That, Pa, Tun, Naing and Tin, take regular medical check-up and medication like one per three or six months. One reason of getting regular medical check-up is the stroke patient’s illness is not long and it around a year. For long illness cases, stroke patients could not go to clinic. They have to wait to do medical check-up and to see doctors if they go. Therefore, the medical technologists visit the house of stroke patients to do required tests. And then, family caregivers go to clinic and show the results and doctors change some medication by looking medical results.

On the other hand, six stroke patients, from cases of Toe, Maw, Htay, Win, Khaing and Soe, stopped treatment and medication. The main reason of stopped treatment and medication is the stroke patients do not feel sickness anymore for long time after stroke. Family caregivers think that stroke patients are well. However, stroke patient from Toe and Khaing cases, do not get treatment and medication because family caregivers think that medication and treatment is not effective for their disease. Toe said that

“I stop giving traditional massage to sister. Now, she takes medicine for hypertension, vitamins and traditional medicines before going to bed. She is well now except swelling legs when she is sitting down.”

The rest of stroke patients do not take regular medical check-up and take some medicines such as pills for control hypertension. Although stroke patients take some medicines regularly, this dose is prescription of doctors when they got stroke time. Later, family caregivers give same medicines with same dose without going to see doctors again. Among them, one stroke patient takes regular medication that is not related with stroke disease. Stroke patient from Aye case takes paracetamol and Bremerton twice a day because stroke patient think that it can good for cough. In addition, depend upon the family’s education, stroke patients receive different caring. Stroke patient from case Myo, Yin and Cho take traditional medicines by buying drug store and traditional medical practitioners. In fact, the cost of buying medicines does not need much spend and can easily buy any drug stores. Aye said that

“Father do not take any medicines including traditional medicines. He always takes paracetamol and Bermerton regularly. If I cannot give him these medicines due to run out, he is angry and throw the things to my kids.”

Furthermore, according to socioeconomic status, stroke patients receive different care from family members. The caregivers from low family income have to do a lot of roles such as working and doing house work besides in caring. So, stroke patients who can walk with stick participate in doing house work tasks when there is no one who can help in caregivers within family. In some cases of low financial income, when the caregivers go out for work, the stroke patients try to help the family caregivers such as cooking for them. Htay and Cho said that

“Husband tries to help me by watching my motorcycle when I leave to sell vegetables. He also cooks rice before I come back from job.”

“When I am out for selling mangoes to town, husband cooks rice and curry. I am worry about him to burn because he cooks them with one strong hand.”



Figure 4.3 Hanging snacks for stroke patient

Figure 4.4 Bed of stroke patient

4.5 Characteristics of Family History of Informants

By accessing the family history, family caregivers received how much support from the family and how they manage the caring tasks can be known easily. It is obvious that five family caregivers from cases of Pa, Yin, Maw, Cho and Soe do less support from family member because they live only with stroke patients at home. Therefore, the family caregivers feel more burnout because they have to do all roles such as caring, working and doing house work alone. They may face difficulties when they want to go out for business or when they feel sick because anyone cannot compensate their role in family.

Moreover, seven family caregivers from cases of That, Than, Naing, Htay, Win, Khaing and Aye do not get family support because all family members are young kids, going to school or adults are working out. It reflects today's lifestyles and living of Myanmar family because almost all family members need to work out to be enough family living. Four family caregivers from cases of Myo, Toe, Tun and Tin come from big family get lots of support from other family members. The rest of four caregivers from cases of Khin, Kyi, Mon and Myint get family support although the family members work out in day time. The family caregivers who receive family support feel less burnout than caregivers without support from family members.

Although some family caregivers cannot support from family members at home, they can seek help from other family members who live separately. Family

caregivers from cases of Khin, Tun and Tin get lots of support by financial and physical from living outside family members whereas caregivers from That, Toe, Pa, Naing and Maw cases, get little support from family members. However, the rest of family caregivers do not receive outside family members support. As a result, family caregivers who receive outside helps are less burnout than others.

By knowing past stroke caring experience of family caregivers, it can know how the family caregivers experience difficulties in caring. Only caregiver from case of Maw had past experience in caring stroke patients in family. That caregiver does not feel any difficulties in caring because of past caring experience. Others from cases of Khin, Than, Myo, Naing, Yin and Tin had past experience in caring of other diseases. The rest of caregivers do not have any past experience in caring. Mostly, they learn how to take care of stroke patients from health care professions and ask caring information of old stroke cases.

In family past stroke case, six caregivers from Than, Toe, Tun, Mon, Yin and Maw cases, had one to three family members suffered stroke in the past. The rest of family caregivers do not have past stroke case in family. So, the family caregivers who experienced family past stroke history are easier in caring roles because they can manage how to take care and who take care by learning from past experience.

4.6 Family System

Family is the basic social group in society. Although every family is composed of many family members, all family members try to harmonize each other as a single unit. To harmonize the family, each family member performs their own tasks under constructed family structure based on family culture. Normally, they do their tasks according to their roles within the family. If the family members experience family problem such as caring of stroke patient for long term, they try to protect by helping each other which do not lead to family broken. Therefore, family has to change former family structure and function such as role shifting or role sharing to balance the family system.

4.6.1 Role distribution based on family culture

Within the family, roles of each family member have been set up according to gender, age and position of family in society. Men have traditionally power over women in the family. As fathers support the family financial and protect the family, they occupy provider roles in a family and hold main authority within the family. Unlike fathers, mothers are main homemakers because they have responsible for housework and also take caring role of children and elderly in family. Therefore, mothers take primary responsibility and fathers have only partial responsibility for day to day parental decisions at home. As a result, mothers and fathers held different positions and both of them have different power within the family.

In this study of caring of stroke patients by family caregivers, the role distribution or assign of roles in the family have also seen according to set up roles of family culture. When women take caring or doing housework roles, men take other productive role such as working role. Htay and Than said that

“Caring by women is good because women are patience and good caregivers”

“No one tells me to take responsibility of caring. I am a girl and I have to take responsibility of caring. Brother helps me, but, he can only help me to drive clinics if stroke sister needs to go. He can't do other house tasks because he goes out for work.”

Furthermore, even though the stroke patients suffer stroke and they cannot perform their responsible roles in family, caregivers and the rest of family members place them in the former roles or position to comfort them. Yin and Tun said that

“I am breadwinner in the family now. But, I make decision of business by discussing with husband. He is head of family and I don't want to feel him inferiority.”

“In the past, she is a cashier of this family and manages family financial status. But, now, I also shows her she is the main of this family and to be happy her by talking in and out of goods and daily income.”

Hence, each family member possesses specific characteristics such as married or single or jobless or having job within the family. Among them, the caregivers who are single, jobless and living same house with stroke patients take more responsibility than other family members. When each family decides to assign the caring tasks according to marital status, most single family members have been assigned in

caring of stroke patients. However, to compare with single and married caregivers, married caregivers have to take more roles than like nurturing the kids and performing husband tasks than single ones, they feel more burdens than single. Generally, the family caregivers take the main responsibility of caring because anyone in family cannot substitute their roles. They are only child of parents or other married siblings or family members are busy with their jobs and family. Kyi, Pa and Khaing said that

“No one has to take care of wife. So I have to. Two daughters live other towns and married children have their own family and busy with their jobs.”

“I take caregiving role because I am single and live with mom in the same house.”

“I am the only daughter and if I can't take care of mom, who will take care?”

Moreover, today lifestyles and family size changed a lot to compare with past in Mandalay. The number of family size shrinks and family type leads to nuclear family in Mandalay. Although some families of participants are extended family types, the family number is small. So, a few men take caring role in this study and they think that taking caring role of stroke patients by women in family should be flexible according to condition of family such as family financial and family numbers. Male caregivers of Kyi and Naing said that

“That rule cannot hold tightly. Caring also depends on family condition. We don't have any girls to take care at home and we don't have choice.”

“Both men and women should take care of role. Care role depends upon the condition of family. If wife has better salary than husband, husband should take caring role.”

The main reason of why the male takes caring role in this research is that there is no women living in the same house while male family caregivers usually live with sons and brothers together. In addition, due to the rest of family members are working out and the family caregivers are usually jobless or working less paid job or retired, males occupy the caring role within a family. However, male family caregivers receive more support in doing house work and caring tasks than female because other family members perceive that doing house work and caring are women duty. For this

perception, male caregivers receive more help than female. One male caregiver receives these kinds of help from the married sister living separate house. Naing said that

“When sister come and visit to the house, she did cleaning, cooking and bathing the mother.”

Finally, in Myanmar family culture, elder brothers and sisters represent as parents by sharing some tasks of parents at home. As they are respectful persons at home, younger ones follow the advice and saying of elder brothers and sisters. Although elder sisters have more power and authority in family culture, they take more responsibility in caring of stroke patients. Family caregivers think that elder sister has mercy to younger sister by working more family tasks and loads. Khin said that

“I take more responsibility in caring mom and I always give mercy and favoritism to my younger sister because I am elder sister.”

4.6.2 Preferring of caregivers based on gender difference

In the study, nineteen out of twenty participants' religion are Buddhism and they believe in modesty. Therefore, caring the stroke patients with opposite sex is improper. The caregivers who take care of the opposite sex of stroke patients are sensitive in bathing and cleaning of sex organ after toileting. Family caregivers prefer women caregivers take care of women stroke patients and men caregivers to men patients because they are sensitive in cleaning of sex organ of stroke patients. Naing and stroke patient from Mon case said that

“Mom gets urinary tracts infection because of weak of personal hygiene. I am a son and it is difficult to clean mom well after toileting.”

“I can tell everything to my daughter about girl things. After finishing every toileting, daughter can clean. But, son cannot.”

4.6.3 Role shifting for caring of stroke patients

Under the family system, the family members make role shifting to take care of the stroke patients. Each family member has to take their responsible roles to balance family structure and functions. Some change from working roles to caring roles and they do both caring and doing house working roles at home. As family caregivers

stopped the job for purpose of caring of stroke patients, it effects the family earning and some lead to financial difficulties. Than and Htay said that

“At first, I work because she can walk with stick after stroke. And then, I left job when sister got bedridden because of broken legs. Now, I do caring and doing housework at home and I don’t have earning after that.”

“I have to stop my job about five years to take care of him because husband needs me to do his daily activities during that time. Now, he can walk and I can work outside. As I stopped working for five years, I have to sell assets and have some debt.”

On the other hand, married family caregivers take three or more than three roles in family such as caring stroke patient, doing domestic work, working out and rearing the children. They are hard to perform all roles at the same time. They have to ignore or less pay attention in one role. When they ignore in working role, it affects the family financial part. If these married family caregivers try to do all roles, they feel tired physically and emotionally. In addition, as they spend all their time by filling these all roles in family, they do not have personal time and leisure activities for themselves. Soe, That, Htay said that

“I can give less time on my farming business because I have to take care of my wife and do house work too.”

“I feel so tired due to take care husband alone and go to work every evening. I also feel disappointed because no one has to help my staffs even buying for something outside”

“My health is different from the past because I have to work under strong weather whether it is sunny or raining. Either my health condition is good or not, I have to work. I have to take care of him even I am sick. My daughter and I cried a lot at the beginning of his illness.”

Some family caregivers have to stop their jobs to take care of stroke patients and have to do caring and doing house work at home. Some have to carry out many roles beside caring roles. Therefore they are facing financial hardship, physical and emotional strain and social isolation.

4.6.4 Balancing the family in caring of stroke patients

Although every family member does not want to the family broken, they try to balance the family during the caring of stroke patients. To balance the family, each family member has to adjust each other by sharing tasks and making decision together in family. Some family caregivers mainly married ones cannot complete their tasks or roles to fill the family requirements alone. They have to pay less attention in one role or lack of doing that role. Thus, other family members help to fill that lacking role instead of caregivers within a family. Khin and Myint said that

“I cannot care daughter well because I have to spend much of my time in caring of mother and working outside. My husband and sister-in-law look after my daughter instead of me. I also make decision about caring mom with my younger sister together. We do it after getting agreement.”

“I have to take care of not only stroke father but also elderly mother. My husband understands me and helps me doing house work.”

On the other hand, there are some disagreements between stroke patients and caregivers or family members and caregivers. The disagreements are concerned with left jobs for caring, different view on treatment types or hospitals during taking treatment of stroke patients. However, family caregivers and all family members try to be balancing the family as one and they change their thinking to reduce the tension disagreement in caring of stroke patients. The ways of thinking are related with family culture such as sympathy, respect and seniority.

According to family culture which descends from generation to generation within family, elder people means grandparents or parents are respectful persons. Younger people have been learned it from the young ages at home. Young people who argue with older people by shouting or saying bad language are very bad and rude manner in the society. Therefore, they usually pay respect and follow the saying of older people in family. They believe that if the young people act or treat badly to elder people, they will suffer that kind of same actions when they are older in the near future. In addition, love, sympathy and respect are signs of filial piety in family. These kinds of family cultural beliefs do not lead the creation of family arguments and also lead to balance the family in caring of stroke patients. Khaing and old aged caregiver of Tun said that

“Mother is making noise by hitting bed at night when she hospitalized. So, other patients and caregivers including me cannot sleep well. I feel angry and scold her about it. After I scolded her, I feel sad. I think I will go to hell in the future because I scold mother.”

“When my wife suffers stroke almost die, her families want her to be back home. But, I want her to stay at hospital. Then, they do not say anything because I am her husband. If my wife complains my caring of best try, I am angry with her. I get lot of sweating due to control my anger. Finally, I forget all because she is a patient.”

When family caregivers try to balance the family in caring of stroke patients, all family members co-operate in caring such as sharing the tasks and making decision together. Moreover, family cultural beliefs like filial piety of respect, sympathy and seniority fill as fact to balance the family in caring of stroke patients. Therefore, family caregivers can balance the family as single unit without getting family broken.

4.6.5 Relationship with family, friends and neighbors in caring

Family caregivers cannot take care of the stroke patients alone and they have to deal with others such as family, friends and neighbors in caring process. Hence, family, friends and neighbors are trustable people for caregivers and their relation is strong by sharing caring tasks or sadness or bad feelings. When caregivers who have open and clear relation with family, relatives, friends and neighbors, they receive financial, social, emotional and physical support. As the family caregivers have good relationship with them, they receive help in caring tasks, financial support for treatment or appreciation in taking caring role by regular visit. If the family caregivers have limited relation with family, they receive less or no support. As a result, types of relationship with family are directly related with burdens of family caregivers in taking care of stroke patients. Tun said

“I have good relation with all family members including son-in-laws. They brought some snacks and gave some money their mom when they visit at home. When they are at home, I do not need to take care of my wife, they do.”

However, having limited relationship of Aye and Myint said,

“I do not speak with brothers because they do not take any responsibility dad from the beginning of his illness. I did not get any help from them.”

“Siblings do not come because I am half-blood-sister. They do not help me both financially and physically. I have to do all tasks. They do not take care just one day.”

4.6.6 Family dysfunction

All family members bond as a single unit by building the family with love, respect and understanding to be a happy and unity family. To harmonize or balance the family, they try to fill one's needs to another within the family by sharing sadness and happiness in the family. Therefore, family caregivers fill needs of stroke patients and they take care of the stroke patients' physical and mental health for long time at home by sacrificing their energy and time. In turn, the rest of family members support the caregivers not to feel burnout in caring process. Hence, if the other family members do not understand the roles of caregivers and do not share the caring tasks, family caregivers feel burnout which leads to family dysfunction at the end.

To balance the family system, as married family caregivers take a lot of roles at the same time, they are difficult to manage doing all roles. If the married couple such as husband or wife do not understand in less care of them or kids, the family function does not balance properly. Thus, family dysfunction or family separation is occurred in that situation. Khaing said that

“If I asked help from other male strangers for lifting mom, we argued that day. But, he didn't help me in caring. Parents cannot be compensated anything in the world, husband can be substituted.”

Although this kind of family separation is obvious, other small arguments are occurred concern with allocation caring task. This thing happens among siblings who take care of stroke parents because they think that all children have same responsibility to take care of stroke parent. Tin said that

“All siblings need to work equally. Youngest brother wants to influence because he thinks he supports money for mother. I do not accept whenever he says to me. If I think it is not fair, I told him back. Other siblings come and visit to mother is for a while. But, I have to take care mother full time.”

Therefore, depending upon types of relationship, perception on degree of responsibility is different. The family caregivers who take care of stroke parent and have

many other siblings perceive that other siblings have same responsibility to take care of stroke parent. If they do not receive support from other siblings, it creates small family conflict even not leading to family separation. However, family caregivers caring the stroke spouse or only child family caregivers think that they are the most responsible person to take care of stroke patient and they do not have any family members who can share the caring responsibility. Thus, family caregivers who take care the stroke spouse and who are only child for stroke parent feel less burden than caregivers with lots of siblings.

All in all, family caregivers live under the family system constructed by family structure and functions based on family culture. Hence, married caregivers take a lot of roles in family at the same time. As they cannot manage all roles alone, they take help from other family members by sharing tasks. If the family caregivers have good relationship with family and relatives, they get much support of financial, social, physical and emotional. If they do not receive any support from family members, it leads to family separation such as divorced or adds the burdens of family caregivers.

4.7 Perception on Burdens

According to constructed family structure and function under family system, family caregivers take caregiving role of stroke patients to balance the family. However, stroke is a long term chronic disease and family caregivers have to sacrifice their time and effort in caring for long time. Therefore, family caregivers experience the some type of burdens in caring of stroke patients. The perception on burden of family caregivers is divided into four parts including financial, social relation, physical and emotional impacts and social services or support of caring knowledge.

4.7.1 Financial Impact

In financial part, the family caregivers sell assets such as gold, house, car, pigs, cows, trishaws, cupboards and all valuable things at home and some lead to debt. Although selling assets such as gold do not disturb the family working process, selling cows and trishaws decrease the family earning because these families depend on those things to run business. Moreover, after selling the house for the cost of treatment and

living, these families face difficulties of living place. The family caregiver who sells cupboards is very tight in family financial because getting money by selling of cupboards cannot get much. That means there is nothing precious things left at home to sell.

In addition, as the stroke patients need family caregivers all the time day and night, the caregivers stop the job and less time on work which add the caregiver debt. Soe and Yin said that

“When my wife feels sick, I cannot work. So, I have to borrow some money with interest.”

“I stop doing job to take care my husband. So, I have to sell a piece of gold, a group of pigs including baby pigs and two trishaws.”

Some family caregivers perceive that they face difficulties in family financial in caring of stroke patients; however, some perceive that they do not get any financial problem. Although some family members think they do not feel burden of financial, they have to sell some assets and spend saving money. Yin, Naing and Khin said that

“I sold some assets such as golden necklace, two sets of gold hand chain for my husband treatment. I sold his car to invest my uncle business. I can live enough by getting money from that business and son’s support money.”

“Mother has saving and I use her saving money for her treatment cost. If she is well, we do not need to spend and we can save 40000 kyat per month.”

“I just take care of mom only physically and I do not need financial support. The cost of treatment is her money. Even if she dies suddenly, some money still has left.”

Moreover, they have to change working lifestyles to take care of stroke patients by quitting job, moving the house to work place, change career, reduce working time and income and lose job opportunity for young caregivers. Than, Pa, Tun, Tin and Mon said that

“At first, I work because my elder sister can walk with stick after stroke. Then, I left job when she lay down on bed because of broken legs.”

“I moved to my work place because I can take care of my mom, at the same time, I can work.”

“I am dealer and I sail ship with goods up and down on the river. I changed my career because of wife’s illness. Now, I store rice at home and sell it if I get profit.”

“I have less time to work as fortune teller because I have to give much time in caring mom. So, it reduces my income.”

“I got job letter to work, but, I choose to take care mom. I think I can work out when I am older.”

In addition, some family caregivers experience difficulties of both their living and family planning. Not only family caregivers but also other family members suffer burden like quitting children education, living old and damage house, live with other family member’s farm. Win, Cho and Htay said that

“When my husband got stroke, I was pregnant. Four children stopped their education and work out for our living, at that time, they are still young.”

“I have to sell a house for my husband treatment cost. Now, we moved to his aunty mango farm. The TLMI (non-government organization) helps and supports money us to build a house in this farm.”

“I have to pay our debt because I could not work out for long time to take care my husband. My earning is not enough and I cannot repair my old damage house to cover rain.”

By looking at the above participants’ burdens, most of the caregivers are married ones. Among married caregivers, caregivers who take care of stroke husbands feel more burdens than caregivers who take care of stroke parent. As the husband or main financial provider suffers stroke, they have to perform as a breadwinner instead of husband. At the same time, they have to perform doing house work and nurturing kids besides working out. Therefore, married women caregivers who take care their husbands suffer more burdens than other groups.

The caregivers who sell assets like pigs, cows, trishaws, cupboard and all valuable things at home more suffer financial part than others. In this group, not only the patients but also caregivers and other family members who suffer some kind of diseases do not get proper treatment for their diseases. Win, Maw and Aye said that

“I couldn't take my husband hospital at that time because I don't have money, my children are still young and I am pregnant of youngest daughter.”

“I bought traditional medicines and take it at home for my kidney stone disease because of financial problem and no one has to care mother when I hospitalized.”

“I sold a house for cost of dad treatment and move this place. Sometimes, I couldn't buy some medicines and eye drop fluid for dad because I don't have money. Now, mom need eye operation because of cataracts, but, we don't have enough money to do it.”



Figure 4.5 The house of the participant in mango farm

4.7.2 Social Relation

In social relation part, family caregivers are less participation in social activities or events like weeding or religion donation, less personal time, less number and less time of outing than before caring stroke. They have to sacrifice their time and effort by caring the stroke patients at home for long time. Therefore, living at home

make the caregivers like prison and lonely because they didn't go out a night trip from three to twenty years long. Naing, Win, Kyi and Toe said

"I would like to take a rest for 15 days and stop caring for a while because I would like to go a trip. I can go a trip just once within four years from the beginning of her illness."

"I can't out social activities for ten years. I can't go out even one night sleep. When mom was sick, I just go and ask for a while. I didn't have a chance to take care of her and have to come back home because I can't leave my husband with my daughter for long time."

"I didn't go out especially trip for three years. I feel I live in prison and I want to visit my home village."

"I want to go out for Hindu God Festival. But I can't, I can't leave her alone at home."

Interestingly, all male caregivers emphasize concerning about burdens that they feel more burden in social part than female. Although male caregivers perceive that they feel burdens in social part because they have not travelled and gone out for long time, female caregivers suffer physical burdens because of taking a lot of roles at the same time. Therefore, male caregivers perceive that they suffer more in social burdens and female feel in physical burdens.

There are other reasons of why family caregivers do not participate in social events. They feel inferiority and no money to donate social events. Some family caregivers think that relatives disregard when they are poor because of stroke. Finally, they do not join any social events. The social events such as wedding or religious ceremonies need to donate some money and some family caregivers do not join these kinds of social events. Win, Cho and Yin said that

"I am poor because of stroke. My relatives are rich and I do not want to participate any social events because I feel inferiority."

"I have to donate or share money for some social events like wedding. But, I cannot afford to donate. So, I do not try to go any social events."

"Father-in-law told me that when I come to their religious ceremony, I should not take to my husband it because he cannot do anything. So, I do not go because I do not feel him inferiority for that."

On the other hand, family caregivers think they do not feel social burdens because they are busy with job or they prefer living at home. Although they do not feel lonely or bored at home, they are less participation in social activities and less time and number of outing than before stroke. Than and That said that

“I haven't out for three months now. I do not have any contact with my friends for long. I don't want to go out because I am old and it is time to stay at home.”

“I do not feel lonely because I am always busy with my job, caring and doing house work. I have no time to feel bored.”

4.7.3 Physical and Emotional Impacts

Family caregivers who suffer some kinds of disease feel more burnout than others in caring of stroke patients. In the physical impact, the family caregivers suffer some kinds of disease such as hypertension, diabetes, asthma, partial stroke, breathlessness, chest pain, bleeding female organ, muscle tetanus, malaria, kidney stone disease and hypotension. They do not get or cannot take proper treatment because of family financial problem, lack of family members who substitute their roles or who can take care of caregivers again. Thus, they have to take care of stroke patient even they feel sick without taking a rest. Cho, Than and Maw said that

“When I got partial stroke and bleeding female organ, I cannot go to clinic because of no money. My stroke husband bought some medicines and he injected me with his one good hand.”

“I was sick and I cannot go to see doctor. My wife cannot help me. She is just a patient. I have to stay at home like that.”

“Although I feel sickness of kidney stone disease, I take care of mother with fixing catheter for two months. There is no one who can do or take care of mom's tasks.”

The family caregivers not only loss of chance of getting proper treatment for their diseases but also feel some physical strains. They feel sleeplessness, loss of appetite, tired, loss weight and headaches. They suffer these physical burdens when caring is long time, no one shares caring tasks, take much caring responsibility by one or no time to take a rest. Than said that

“Although I reduce weight because of loss of appetite, my stroke sister gains weight day by day. Now, I can't lift her well.”

Among caregivers, female caregivers suffer body pain, leg pain and arm pain because they lift the stroke patients up and down a lot of time for long time. But, male caregivers do not suffer that kind of body pain in caring of stroke patients. Myint and Win said that

“I feel pain in my arm because dad is fat and difficult to lift him.”

“Sometimes I feel pain because of lifting him up and down for 10 years and I don't want to move my body and arms.”

As mentioned above in belief system, women take main caring role within a family. As women have to handle many roles such as caring role, doing house work, working and nurturing kids at the same time, they feel more burdens than men caregivers.

Some family caregivers have to take care of both stroke parent and elderly non stroke parent at the same time. The family caregivers who take care of both stroke patient and other elder people feel collapse and they want to stop caring or want to run away. Myint and Aye said that

“I have to take care of both mother and stroke father at the same time. Sometimes, I would like to run away because there are lots of tasks to do. I think myself do I have to feel always sadness like that.”

“Now I have to take care of both parents. Mother also feel cataract both eyes. I cannot sleep at night because she often calls me when she feels pain. I do not have time to take a rest.”

In the emotional impact, they feel dispiriting, depressed, bored, lonely, confinement and inferiority when caring is long time, no one shares caring tasks, take much responsibility by one and no time to take rest. Win said that

“Taking responsibility of caring stroke is too much burden. Some people told me that I can die instead of my husband. I feel confinement at home.”

Adding worry about stroke patients with suffering of above emotional burdens makes the family caregivers collapse. Some caregivers are afraid of losing stroke patient to die whereas others want to let the patient die because they do not want to see the loved ones suffer the disease for long time. Aye and Kyi said that

“I am afraid of mom die. When I am away her, she die without knowing me. I am not thinking of her death and I don't know I can stand or not after she died.”

“I want to let her go because she suffers pain here and there. I don't want to say other people's life, but, I assume that it is good way that she can escape quickly from that suffering.”

Some family caregivers collapse a lot and they try to find out to escape way like leaving the stroke patient alone by locked the door outside and think to suicide. On the other hand, they worry about the patients leaving at home with other family members or paid-attendants. Khaing, Cho, Win and Myint said that

“I feel confused without going out for long. So, I locked mom at home alone and visit to my friend. After I told my feeling and condition, I cried a lot because of sadness.”

“When he got stroke, I cried a lot behind him because I don't want to him to be sad. Sometimes, I think myself to die to escape from suffering.”

“I worry to leave him at home. That worry is different from other worries and it may burn my body. So, I do not try to go out.”

“Within a week, I feel depression a lot of times. I would like to stop without doing anything, but, I can't leave dad and I worry about him.”

Although all family caregivers take care of the stroke patients, their perception especially emotional part is different according to socioeconomic status. The family caregivers from poor socioeconomic status feel happier and more satisfied than caregivers from high income family. The main reason is their requirement is simple and they want to get basic needs of living such as repairing the house and mending the hole of house. The family caregivers from high socioeconomic status also possess high education level at the same time. They feel that they lose their own life and future personal development such as quitting the job, loss of opportunity to get job in young age. For these reasons, they do not feel as happier as family caregivers from poor socioeconomic status. Than said that

“I was aggressive and argue with my brother because I left job to take care of sister at the beginning.”

4.7.4 Social Services

For perception of social service and caring knowledge, it mainly access what kinds of support the family caregivers receive from government such as health care

services or financial support or health care knowledge support for caring of stroke patients and how the family caregivers perceive these kinds of support. If the caregivers do not receive enough support such as poor health care service support or poor health care knowledge support, that leads the family caregivers to trap in burdens. Myanmar people can take treatment from public hospital, private hospital, clinic, traditional medicine hospital, traditional clinic and traditional massage at home. Mainly, they need support of medical treatment, financial and health knowledge for caring.

Some think that public hospital is cheap, lots of medical machines and doctors serving whereas private hospital is good services, no time limit and number of attendants and can choose doctors. The family caregivers who chose clinic and traditional medicines treatment at home because they are not affordable for treatment or cannot waste one people work force in hospital or parents are afraid of to take treatment in hospital.

For support of medical treatment, Naing, Htay, Aye and Khaing said that

“Private hospital has good service, every staffs care well seriously when you pay well. Public hospital can't compare private hospital.”

“I prefer taking care patient at home. I don't like hospital because patient can't take traditional medicine and treatment at hospital and staffs and doctor may scold.”

“My parents are afraid of hospital and they want to take treatment at home.”

“I prefer public hospital because I know the hospital rules and professor have to work at hospital all day and in private clinic, doctors don't have any time and have to call if need.”

For financial support, That, Tun and Win said that

“The cost of treatment is not much in public hospital because some medicines got free, paid less room services fees and doctors also take care well.”

“The difference between private and public hospitals is the cost of treatment. In public hospital, it is very cheap. By compare the cost, the public hospital is better than private hospital.”

“I prefer taking care patient at home because I can't afford to pay the cost of treatment at hospital. If husband admitted hospital, one family member has to stay with him. I could not spend one's working force there.”

Family caregivers choose the health care services according to the different family socioeconomic status and providing health care services to public from government and private sectors. When the family caregivers utilize private health care services, they feel financial difficulties because stroke is long term disability disease. The family caregivers who utilize the public health care services feel tiredness because they choose poor health care services with low treatment cost. In addition, lack of health care knowledge adds them to feel burdens. Some participants think that they do not get proper health care knowledge and want to get it from health care professions. Mon and Kyi said

“I don't know how to take care when mom chock. I have to ask doctor about it.”

“I would like to get help from social health care workers because they are professional people and know how to take care stroke patients. Their caring is different from paid health care workers and family member.”

To sum up, family caregivers experience selling assets, debt, changing working lifestyles, delay family development planning and not getting proper treatment because of financial difficulties. Furthermore, family caregivers face less or lack or social events, less personal time, outing and travelling and feeling lonely. Moreover, family caregivers suffer arm pain, headaches, tired, worry, willing to run away, willing to suicide, depressed and inferiority. Finally, family caregivers want to get proper health care knowledge from health care professionals.

Table 4.3: Summary of Perception on Burdens

No	Financial	Social Relation	Physical and emotional impacts	Social services
1	Sell assets for living and treatment, debt	Less or lack participate in social events	Sleeplessness, arm pain, tired, loss weight, headaches	Medical- seek good services, good doctors, traditional

				medicines and massage
2	Quit job, change career, reduce working time, lose job opportunity	Less or lack personal time, outing and travelling	Not get proper treatment caregiver and other family members too-No time and money	Financial- seek cheap, chose traditional medicines- unaffordable of treatment cost
3	Quit children education, live in old damage house	Live lonely and like prison at home	Depressed, lonely, dispiriting, inferiority, confinement, worry	Caring knowledge-not get proper from professionals and want to get it
4	No money- not get proper treatment		Willing to run away and willing to suicide	

4.8 Family Beliefs System

Although family caregivers suffer burdens in caring of stroke patients for long time, family beliefs system mitigates the burden of family caregivers. Family means each family member provides emotional and spiritual kinship through shared values and beliefs within family. Family value and beliefs based on culture in caring of stroke patients create unbroken family. In family value, family members do not try hurting others and they support for family members who cannot stand up for themselves. Family value and beliefs of caregiving, family belief on stroke (disease) and sense of mastery are divided under the family belief system.

4.8.1 Family Value and Beliefs of Caregiving

Family value and beliefs of caregiving mainly talk about perception on family and caregiving. Family value makes all family members live as one unit to build happy and unity family by sharing tasks. They share sadness and happiness each other and help each other by filling one's needs or weakness to others. In addition, they give love each other and forgive mistakes by speaking openly what they really want. Tin told that

“Family needs understanding. Money can earn easily, but, family cannot bond as a single unit without understanding in family.”

However, some family members think that family is not only filling with good things. Naing said about value of family by sharing of tasks,

“Family has good and bad things. Some know and take responsibility, but, others do not. We should take own responsibility.”

The beliefs of caregiving mainly discuss about ‘karma’. People who believe ‘karma’ accept three things, causality, ethicalization and rebirth. Karma is executed or planned action. Firstly, karma discuss about causality which may be ethical or non-ethical. Good action creates good karma and bad action creates bad karma. In this step, present circumstances of an individual refer to his or her actions in the past. Htay said that relationship of stroke family come from the past life.

“My husband and I meet in this life because of effect of past life. So, we have to do each other tasks.”

But, some caregivers think that caring role is ‘bad karma’ or ‘wit kyae’. They think that suffering by caring is their past bad actions and they cannot deny it. They have to pay back it till ends. Kyi and Tin said that

“I take care of my wife because I have bad karma or ‘wit kyae’. I owed my wife in past life or did bad things to her. So, I have to pay it back now.”

“Caring is my bad karma and I have to pay that bad things till end in this life.”

The consequences of current actions may result in current life or future lives. Secondly, karma showed as ethicalization such as every action has a consequence. But, karma itself not represents reward and punishment. Good karma leads to merit and bad karma leads to demerit. It depends on actor's intentions, attitude and desire before

and during action. Finally, karma represents rebirth or reincarnation. All life forms go through a cycle of reincarnation that is a series of births and rebirths. The condition or form depends on quality and quantity of karma.

If the family caregivers take care or treat well the patients, they will get good karma or merit or 'ku tho'. If the family caregivers take care or treat bad the patients, they will get bad karma or demerit or 'going to hell'. Yin said that

"From the religious point of view, I will get merit or good karma or 'ku tho' by caring my husband."

When family caregivers who take care with impatience or yelling patients, they will get demerit or bad karma or going to hell. Khaing and Tin said that

"By caring mom, I also got bad karma or going to hell because I yell mom. But, I do not want to tell her like that. Everything I did will be gone if I treat impatient and yelling her."

"By caring mom, I will get the amount of getting good karma is one ounce. The amount of bad karma or going to hell is 100 ounces because sometimes I feel angry during caring mom. I have to do all tasks alone and no one help me."

In addition, if the family caregivers leave the stroke patients without taking any responsibility, they will feel that kind of situation in the future such as there is no one to take care when they feel sick. Cho told that

"If I leave my husband without taking any responsibility, I will get bad karma that means I will suffer like him when I feel sick. No one will take care of me when I feel sick."

Finally, the family caregivers believe that they will receive good karma or merit or 'ku tho' in the current life or future life. Maw and Khaing said that they receive the effects of caring their mom well during this life.

"I need operation for kidney stone disease. But, I cannot hospitalize because mother will be at home alone and no one has to take care. Now, I do not need to take operation and my disease is better because of caring mom well even I am sick."

"I can live without worry about financial because of effect of caring mom. If I do not do daughter duty, I cannot live like that."

All in all, the family caregivers believe that caring the stroke patients and suffering burdens is their bad actions in the past life. They have to take care the patients

till the bad karma ends. However, by caring the stroke patient well in the current situation, they will get merit or good karma. The result of good caring experiences in the present life such as caregivers get good health and good financial condition. They have to take responsibility or caring is their duties. If they leave patients without taking any responsibility, they will face same situation when they feel sick. If they treat patients badly, they will get 'bad karma' or 'going to hell' for that action.

Therefore, family caregivers perceive that the burdens from caring roles related to karma. These burdens cannot be avoided. Besides, beliefs in karma mitigate the feeling of burdens as they could expect they would get better things in the next life if they take care of patients well. That kind of belief is a kind of emotional coping and which makes the family caregivers to relieve from burdens. That belief drives the caregivers to work more in caring role and working role.

4.8.2 Beliefs on Disease

By accessing the cause of disease, family caregivers' health knowledge and their perception on main cause of disease can be easily known. Mainly the cause of disease is divided into five things which are because of disease, because of patients, because of caregivers, because of other outside people, because of outside things. Mostly, family caregivers think that the cause of disease is because of hypertension and diabetes. Some caregivers blame that the cause of disease is because of stroke patients. The stroke patients are drinking, smoking and not taking regular medication. Tun and Win said that

"No one knows she suffer hypertension and she didn't take medicine because she is afraid of taking medicines. Although she went to clinic before stroke, she threw medicines that doctor gave her to take."

"He drinks alcohol when he comes back home from work. He got stroke because he didn't listen to my advice like stop drinking and eating salty foods."

Some caregivers blame themselves. The evidence of that blame is that the caregiver is less take care of the patients, living away the getting stroke time and doing action of the stroke patients dislike. Therefore, they feel sorry for stroke patients because of their actions and they take main caregiving role too. Aye said that

“He got stroke after I said I am getting married soon. I think my marriage new also includes in getting stroke. He dislikes my marriage because I am only daughter.”

Some caregivers think that doctors do not tell them it is signs of stroke when they take treatment at first. They think that if the doctors say early to take treatment, stroke patients cannot be worse like now. Kyi and Yin said that

“She has muscle weakness and she drops things hands. Although she takes treatment for that muscles weakness at hospital, doctor didn't told me it is beginning the sign of stroke. If he told early, we will go and take treatment from neurological specialist.”

“I waste time at home a day because family doctor said husband didn't need to go hospital. His family advised me to go and take treatment from family doctor. According to my will, I will go hospital first.”

The last reason of cause of disease is outside things. For instance, eating wrong foods that can increase blood pressure, bathing immediately after come back outside under sunshine, drinking cold water and angry people got stroke. Than and Cho said that

“She is angry that is why she got stroke.”

“He got stroke because he took bath with lots of sweating after coming back from work. The weather in upper Myanmar changes too fast.”

Family caregivers believe that these actions can cause stroke disease. Because of this belief or perception of cause of disease, they do not feed these kinds of foods to stroke patients. Moreover, family caregivers do not eat or do not do these kinds of actions because they are afraid of suffering stroke disease themselves. These kinds of action also related to coping ways especially behaviour coping.

In addition, stroke is a long term disable disease and family caregivers perceive the stroke disease from religious aspect, medical aspect, family aspect and emotional aspect. In the religious aspect, the disease is caused by ‘bad karma’. Kyi and stoke patient from Soe case told that

“Stroke is bad among chronic diseases. It is ‘bad karma’ or ‘wit kyae’ disease because patient may suffer disease 10 or 15 years depending on quality of caregivers’ caring.”

“I suffered stroke disease because of bad karma. Maybe I killed animals in my past life.”

When looking at the medical side of view, it is long term disability disease and stroke patients suffer disease with disorder of physical, mental and social till they die. Pa, Toe and Cho said that

“Stroke is suffering of physical and mental disorder disease because patient cannot move, cannot speak and cannot control bladder and bowels although they want to do.”

“Stroke is a suffering disability disease till death. All daily activities depend on others.”

“From the patient side, he cannot move and can feel depressed in thinking of can I get recovery? Patient cannot do by self what he wants to do.”

From the family side of view, it causes the tired of financial, physical, emotional and social of family members. Naing, Win, Than and Nyut from Aye case told that

“Stroke is very terrible disease. Firstly, it needs money, then; it also needs full time caregivers.”

“Caregiver’s life is death along with the patient’s life at home. But, caregivers can eat and drink whatever and whenever to compare with stroke patients.”

“Stroke is not good for caregivers because caregivers have to take care of the patients for long time.”

“Stroke is not a recovery disease after getting it. Stroke causes people to be poor and hungry.”

Emotional aspect looks at physical manifestations of the disease like pain or non-pain disease or alive or death disease by comparing with other disease like cancer. Stroke is better than cancer because family members do not need to see pain of stroke patients. Stroke can get recovery and patients can live longer than cancer. Myo, Htay and Tin said that

“I experienced in caring of cancer sister. To compare with her, I feel better mom’s suffering stroke because my sister suffered a lot of pain and I could not see her pain.”

“Stroke is long term chronic disease. But, to compare with cancer, stroke can get recovery.”

“To compare with cancer, stroke patient can live longer than cancer. Cancer patient can die within a year, but, stroke patient can live how long he expects to live.”

In conclusion, family caregivers believe that stroke is a bad karma disease and long-term chronic disability disease. It causes burnout of family members including financial. Stroke is less pain and live longer disease than cancer. Family caregivers perceive severity and suffering of disease by physical symptoms such as pain and alive. Patients with stroke might have less bad karma than cancer as they do not express the pain or patients can live longer than cancer. Hence, the illness of stroke may be perceived as causing relatively less burdens as compared to the other diseases.

4.8.3 Sense of Mastery

Under the sense of mastery, ability or internal locus of control shows the family caregivers' internalized feeling on stroke patients. In social and cultural support or external locus of control by others express perception on caring by family supports and cultural meaning. The last one of caregiving role or internal locus of control by self-discusses family caregivers' internalized belief on taking caring role based on family beliefs.

4.8.3.1 Ability

The ability shows that family caregivers take care of stroke patients because of affection and attachment. Mostly, they take care of the stroke patients because of love and respect. Myint, Myo and Than said that

“I love my father. Although we did not chat much, I love him.”

“I respect my mother because she took care well her parents and uncles when they feel sick. So, when she feels illness, I care her well.”

“I can take care of my sister by putting mind and effort because I love her. I love her more than other siblings because both of us are single. I feel satisfied of she is alive and live with me how much do I take care.”

However, others do not show their love and respect to stroke patients and they show family attachment alternatively instead of affection. They show

their attachment by perceiving caring is duty and pleased living with patients. Living with stroke patients with physical disability makes the caregivers strong and safe. Tun, Kyi, Khin and Khaing said that

“I feel my wife is my colleague because she lives with me all the time when I sail in the river for trading goods. That attachment and relationship are main reason of not saying grumble about her illness and caring. I can care her for long because of love and family values including sympathy.”

“I don't feel caring is a burden and I do not find ways to escape. It is my duty and I cannot deny it.”

“Although mom cannot do her tasks herself, I am happy because she is alive and living with us. I did everything that good for her because I do not want to regret when she passed away.”

“Although mom can't move and can't do her daily activities herself, living alive like that make me strength. Living with us feels me safe and give strength to me.”

The family caregivers take care of stroke patients not only affection and family attachments but also morality. The family caregivers who think about the morality take care of stroke patients because they do not want to regret after parents death. Tin said that

“I had experienced of regret. I did not care custodial mother till she die. I felt lots of regret and sorry after she died. I do not want to feel like that for my birth mother.”

If the family caregivers think that family bond is a single unit, the relation and love change such as wife thinks and treats husband patient as brother or uncle. Alternatively, as married couples change their attachment type, they can take care of stroke patients well for long time without grumble. Yin said that

“I argued and fought with him when he is well. Now, I care him like my brother even if he told me bad language. If I feel he is my husband, I will argue with him. If I think he is my brother, I am patient to take care of him.”

To sum up, family caregivers take care of the stroke patients without grumble or without finding to escape because of love and respect. Moreover,

they think that suffering of burdens relieves for them because they care the stroke patients with love, respect and family attachments.

4.8.3.2 Social and Cultural Support

Family caregivers perceive caring the stroke patients based on family supports. In social support, the family caregivers receive financial, emotional and physical support from family members including neighbors. The receiving amount and number of support is related to family type, degree of boundaries, caregivers' burdens, education, occupation and socioeconomic status. Family caregivers receive the physical support such as taking care role when stroke patient in hospital or when caregivers need to out. In married couple, husband or wife helps to take another role like looking after kids. Kyi, Pa and Khin said that

“Relatives, sons and daughters take care of my wife when she hospitalized. I do not need to take care of her in hospital. At home, son and I take care of her. As I get help a lot from my son, I do not feel caring is burden.”

“Lots of relatives come and take care of mom in hospital. Sister helps me a lot. Without her and relatives' help, I cannot take care of mom alone.”

“Husband and sister-in-law look after my daughter. I can't care her well because I have to give more time to take care of mother.”

Some caregivers receive little help or support from family. They can blame or be angry on that little support from family members. But, they perceive positively about getting that little support. Cho and Tin said that

“My relatives also support foods like onion, chicken and rice. His and my relatives are poor and they can afford to give me like that.”

“Single elder sister helps light care like give drinking water, feeding foods and sleep with mom at night. She can't take care mom that much because she suffers diabetes seriously and weak.”

Family caregivers usually receive appreciation about caring from family members, relatives and neighbors as emotional support. If they get recognition on taking caring role of stroke patients from family members, they feel pleased on getting a certain place within family without receiving ignorance. Naing said that

“Siblings cannot help me physically because they are married and live away. But, they appreciated my caring. They told me that mom is good because I care her. They say thank me.”

Family caregivers receive financial support like giving money the cost of treatment when the patient hospitalized time. It seems the family caregivers receive financial support from family which also means emotional support like giving foods or medicines in lower economic status family. Whereas the support of foods and medicines cannot solve financial burdens well, it means that other family members, relatives and neighbors encourage the caregivers in taking care role in family. Maw and Aye told that

“Single cousin supports money for living monthly. He takes me clinic when I feel sick. Whenever I need help and problem, he comes to me anytime. I feel perfect and strong when he is near me.”

“Neighbors gave me some medicines, traditional medicine liquid and curry. We can live because of good neighbors.”

In one hand, family caregivers feel thankful and think positively about the little support from other family members. On the other hand, their perception on some kinds of family support is not helpful in caring and that kind of support is not enough for them. Naing said that

“Brothers and sisters can afford to support financial but they can't take care mom for long time. I don't care that much seriously only I have to take care, but, sometimes I feel angry. Eldest brother told me with phone that if mother feels sick, tell him and I do not need to worry about money. That means that only mother feels sick, he support money. That is not good. The right way is whether mother feels sick or not, he must pay or support regularly.”

In cultural support, although family caregivers suffer some kinds of burdens, the belief on cultural support feel them to ease these burdens. These beliefs or perception descend from culture, family history and religion. They think that caring stroke patients for repay of debt of parents and it is children's duty. Khin and Tin said that

“When I was young, mom did all tasks for me. Now, it is my turn and I don't feel I cannot care mom like she care of me when I was young.”

“I can't leave my mother without taking care because she is my mom. I have to do with full responsibility whether I want to or don't want to. I am her daughter and I need to repay the debt of parents. This is children's duty.”

For the married couple, caring is keeping marriage commitment and family duty. Win and Cho said that

“He kept the marriage commitment when he is well. He worked out to earn enough money for family living. I do not need to work out. Now, if he felt sick, I have to care him again.”

“I can't leave my stroke husband because caring husband is wife duty. If he can't die within 30 or 40 years, I have to take care of him because he is my real family member.”

The ancestors send the caring by family culture hand by hand to next generation. Family caregivers heritage the sense of caring on chronic patients from mother because mother takes care her parents when the caregiver was young. Religion teaches the people to take care chronic people. Pa, Myo and Kyi said that

“I get sense of caring from firstly from religion. Secondly, from mom, mom takes care of her mother well when her mother was sick. I learn it from mom.”

“I get the sense of caring older people by younger ones from mom. Mom takes care of my grandparents very well and she becomes an ideal woman for me.”

“I get the sense of caring from teaching of religion, studying and my own thought and thinking.”

In conclusion, perception of burdens of family caregivers change and they feel that burdens diminish because they get support from family and they feel perfect and strong. In cultural support, family caregivers take care of the stroke patients because of repay of debt of parents, marriage commitment and family duty. Therefore, family caregivers perceive that caring is their duty and responsibility. Although they feel burdens in caring of stroke patients, they take care because stroke patients did good things in the past. Stroke patients look after caregivers when they are young or they are good husbands or wives in family. That belief also link with karma. As a result, the

stroke patients did the good things to caregivers and caregivers take care of the stroke patients.

4.8.3.3 Caregiving role

There are two things of beliefs on why the family or family caregivers take main caring role. One belief based on other family members and environment. Family caregivers perceive themselves; as they are more patience and kind to compare with other family members, they take the main family caregivers in family. In addition, they take main role because they are afraid of blaming of relatives and neighbors around the environment. Mon, Yin and Nyut from key informants said that

“I am patience and I think caring by patience people is good for both stroke patient and caregiver.”

“I take full responsibility. For that I am not tired and I have clear conscience to husband and his relatives. I can live proud of myself among neighbors and relatives because I take care of husband well. If not, they may have chance to say sarcasm.”

“I take care of my husband and work out as a massager because of our attachment. If I didn't take responsibility, people will say sarcastic to me.”

The second one derived from family culture and caregivers perceive that caring the patients by family members is good way of caring. Patients can get warm, love, kind, strong, good caring and not feeling stress from family members. They think caring by family members shows love and sympathy in community. Yin and Tun said that

“Caring by family is good. Whatever poor or rich, patient can get kind and good caring from family.”

“I feel taking responsibility by patients themselves in caring role is materialism.”

To sum up, family caregivers take main caregiving role because of influence of characteristics of family caregivers, environment and family culture. Family caregivers perceive themselves that caring is family tasks. Among family members, they receive caring roles is theirs in family. They do not deny or reject the caring roles and they accept it. Therefore, the family caregivers feel relieving burdens in caring of stroke patients because of that positive thinking.

Table 4.4: Summary of Family Belief System

no	Family value and belief of caregiving	Family belief on stroke (disease)	Sense of Mastery		
			Ability	Social and cultural support	Caregiving role
	Perception on family and caregiving	Perception on stroke disease	Internal perception of caring	External perception of caring from family and culture	Internal perception of caring by self
1	Family value- one unit- share sadness and happiness	Bad karma disease	Care with love and respect	Social- perception on help of family by financial, emotional and physical	Take role by environment and special ability of family caregivers
2	Care the patient as did bad actions in the past	Chronic disable disease	Care with attachment	Cultural-perception on care by culture (repay of debt of parents, family duty and marriage commitment)	Take role by caregiver- give warm and good care to patients
3	Take care well- good karma or merit	Family burnout disease	Care with morality; not regret	Cultural- teach care the elder chronic family members by parents and religion	
4	Take care bad- bad karma or going to hell	Less pain and alive long disease			
5	Leave patient- bad				

	karma or leave like that when feel sick				
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4.9 Coping Ways

Family caregivers try to cope with the burdens with behavior, social and emotional aspects. They think themselves that they are the main persons for family and stroke patients. Therefore, they do not want to feel any sickness and they want to take care of stroke patients full of efforts with peaceful minds by coping with their burdens.

4.9.1 Behavioral Coping

For behavior coping, the family caregivers care their health after stroke by sleeping in the day time, doing exercise, taking vitamins and minerals, eating nutritious foods or eat a lot and not eating unhealthy foods. By doing these kinds of activities, they try to cope to compensate sleeplessness and tiredness that lead them to be healthy.

Some recreational actions like watching TV, reading, listening to music, singing, dancing and playing games reduce physical tension. Other normal people who do not take caring role do these kinds of recreational activities; however, stroke caregivers do these kinds of activities to reduce their burdens of caring within certain limit of time. Going shopping, going and sitting tea shop, going outing and sitting in cool and quiet place at home with fun include not only behavior but also emotional and social coping. Than, Tun and Pa said that

“To compensate my sleeplessness and dizziness, I take vitamins and mineral. I care my health including foods and doing exercise. If I feel sleeplessness tonight, I sleep more tomorrow. Watching TV reduces my stress.”

“I care my health because wife needs me. I go out for a while if I feel angry her until my angry let go.”

“If I feel angry or lonely at home, I listen to music, sing songs, dance, watch comedy movie and go shopping. These activities reduce my stress. If I feel depressed, I read book.”

When looking at the coping way of family caregivers from high family financial status, they usually more spend time in recreational activities such as watching movies, listening to the music and going outing.

Furthermore, family caregivers do not let them to be sick. They take medicines like pain killer when they feel certain signs of sick before they are really sick. Some caregivers changed their appearance to be nice and good looking to cover the physical and emotional tired. Finally, some caregivers do the tasks non-stop without getting thinking time. In fact, the family caregivers from poor socioeconomic status use different coping way. As they are poor and anyone cannot compensate their role within a family when they are sick, they try to take medicine before sick or do the tasks non-stop without giving time to think of sad past time. Win, Yin and That said

“If I fall and feel sick, my children will be more burdens. So, if I feel body aches, I take medicine before I feel sick.”

“I wear traditional make-up and flowers to be good and fresh every morning because I do not want to see my sad and untidy face to my family. By wearing like these, my husband and children may think I am strong.”

“I do a lot of tasks without having thinking time of difficult situation.”

4.9.2 Social Coping

For social coping, most family caregivers seek help from others such as family members, friends, neighbours and doctors by visit their house and tell the problems and feeling. They try to participate social activities like wedding, funeral or friend gathering at school to get constant contact with friends and relatives and try to use updated social coping like phone and using social media site. Khaing, Pa and Than said that

“I have close friends. If I feel so stressed at the beginning of mom's illness, I went her house and tell my problems.”

“I can contact with my friends via line call and social media like face book and chatting in message box. If I feel tight in my mind and get stress, I phoned my friend for half an hour and sometimes I visit their homes to tell my feeling and situation.”

“I try to go out friend gathering because I do not feel social isolation. Now, I am a member of social group at school and go out for social activities.”

Specifically, family caregivers from different gender and socioeconomic status use different coping ways. The male family caregivers try to do more in social coping such as visiting to the friends or relatives or travelling. In the same way, family caregivers from high socioeconomic status use much social coping way especially visiting and communication to the friends or relatives and participating in social events.

4.9.3 Emotional Coping

Most family caregivers try to cope with emotional burdens by religion such as praying, go to pagoda, meditation, listening to 'dharma', sharing love to Gods and all human beings and sitting in front of Buddha image for a while. They do religious things such as donating flowers, foods, water, light candle, Sabbath and do rosary. Pa and Soe said that

"I pray and listen to dharma of monks, donate flowers the God. If I want to get peace, I sit in front of selves of Buddha image for five minutes."

"I do religious staffs by donating foods, flowers, light candle and drinking water to God because I feel peaceful by doing these religious staffs. I go to the pagoda."

However, the female caregivers try to do in emotional coping such as doing religious things at home or praying. Female caregivers try to cope burden with emotional way whereas they suffer more burdens in physical part because they do not receive enough physical support from other family members.

The positive thinking is a way of emotional coping such as caring is in God will, caring is bad karma, think happy past family time, caring is my duty, stroke is a common disease, every people have to die, illness is stroke patient's fate. They think caring to stroke patient and getting disease is out of control. Kyi and Khin said that

"I think myself, stroke can suffer every person and it is a common disease. It is not a disease of suffering one person pre a million. I don't think it is burden because it can be bad my health condition."

"Although I worry about mom will die, I think myself according to my religion, it is in God will and I pray for her."

Auto self-suggestion is another way of emotional coping. They think themselves that they are important persons in family, all tasks can finish by caregivers, face any difficulties in the future without getting any worry now. Toe and Yin said that

“I do not feel burden because I think myself this is my duty and every work including caring and doing house work can be finished up because of me.”

“To strengthen my mind, I always think I am main person of this family. I can't deny this problem. My husband and two kids depend on me and I have to strengthen. If I think the happy time of family in the past, I feel better.”

In conclusion, family caregivers try to cope with the burdens by behavior, social and emotional coping. In behavior coping, they take care their health than before stroke, do recreational activities, take medicine before sick, wear good clothes and flowers to be strong appearance other family members' view and do the tasks non-stop without getting thinking of difficult situation. In social coping, they try to visit family and friends or call and use social media sites to tell their problems and feelings and participate social events for not getting social isolation. In emotional coping, they try to do religious staffs, think positively and auto-self-suggestion to be peaceful and strong.

Table 4.5: Summary of Coping Way

No	Behavioral Coping	Social Coping	Emotional Coping
1	Care health than before	Visit family and friends	Do religious staffs
2	Do recreational activities	Participate social events	Think Positively
3	Take medicine before sick	Call and chat with friends	Auto-self-suggestion
4	Wear to be good looking		
5	Do the tasks non-stop		

CHAPTER V

SUMMARY, DISCUSSION AND RECOMMENDATIONS

5.1 Summary

This study is to characterize the family belief system shaping the perception of family caregivers' burdens in taking care of stroke patients and how to cope the burdens. To explore the beliefs and perceptions of family caregivers in taking care of stroke patients, qualitative, explanatory is used. The utilized method for data collections were open-ended in-depth interviews and participants observation at the caregivers' houses. Twenty participants, who were family caregivers in taking care of the stroke patients from eight months to twenty years long and nine key informants, who were one of family members or stroke patients, were interviewed as data sources by purposively selected. Informants' interviews were carried out with 9 daughters, 5 wives, 2 sisters, 3 husbands and 1 son. Research was conducted in Mandalay, Myanmar which is high mortality rate of stroke in Myanmar.

Among 20 informants, middle aged married women are mostly occupied in caring role in family because they become main internal household of the family and they become physically and mentally mature at that age with full of experience within the family. As these family caregivers take full time caring role, they cannot do full time job and they have to choose part-time jobs or home-based business such as opening grocery store at home. In addition, most family caregivers are situated in low education level. The main reasons of why these people become the family caregivers within the family are low education and economic situation to compare with other family members.

By looking at the stroke patients and disease, almost all of stroke patients are elderly or retired aged. As the stroke patients are elderly, they need more support or help from family and government. According to the degree of disability and illness time, the family caregivers who take care of bedridden stroke patients for long time suffer more burdens than others. Moreover, as the family size in Mandalay shrinks, the family caregivers are less or lack support from other family members in caring role. In some

cases, although some family types are extended type, the family number living in the same houses is small. As a result, the family caregivers feel burnout in caring of stroke because of less or lack of family support or sharing tasks of caring role.

5.1.1 Perception on Burdens

Stroke is long term disability disease and stroke patients need the family caregivers for long time. As the family caregivers have to take care of stroke patients for long time, they experience some types of burdens which are financial, social, physical, emotional burdens and poor social services. In the financial part, the family caregivers have to quit the job or change career or reduce working hours since the stroke patients need one family member full time. That effects the financial situation of both family caregivers and other family members. In fact, young family caregivers have to lose job opportunity in their young ages as they have to spend their time in caring of stroke patients at home.

While the family caregivers take care of stroke patients day and night without working out for long time, they have to sell assets such as gold, car, house, cows or pigs for the treatment of stroke patients and living. When the valuable things run out for selling, they have to borrow money with interest. That leads them to debt. Hence, if the stroke patients are breadwinners, these family members experience more difficulty in financial part than others. As a result, the stroke patients do not get proper treatment because of difficult family financial condition. Due to the effect of stroke disease, not only stroke patients and family caregivers experience financial burden but also other family members suffer effect of financial burden. If the breadwinner in a family suffer stroke, children have to quit the school and work out for family living and all family members have to live in old damaged house.

In social impact, as family caregivers have to spend their time and effort by sacrifice themselves in taking care of stroke patients, they are lack or less of personal time, outing and travelling. In addition, they are also less or lack participation in social events such as religious ceremony and wedding. As they live at home for long time by caring of stroke patients, they feel loneliness and living at home is like a prison. There are some reasons why the family caregivers do not join the social events. As people need

to donate some money in some social events, the family caregivers do not participate because of family financial difficulties. Some family caregivers feel inferiority to join social events because stroke disease drags the family to be poor socioeconomic status.

In the physical and emotional impacts, family caregivers feel sleeplessness, tired, loss weight and headaches because they take care of the stroke patients not only in day time but also night time such as for toileting. As female caregivers have to lift up and down the stroke patients many times per day, they feel arm and body pain. Some family caregivers suffer some kind of diseases such as hypertension, diabetes, asthma or kidney disease and they are facing difficulties in caring of stroke patients. Among the family caregivers, elderly caregivers who are suffering some types of diseases face physical burdens than others. Not only stroke patients but also family caregivers do not get proper treatment because family caregivers do not have enough money and time to take treatment and no one can compensate the caring role within the families during hospitalized. Since some family caregivers take care of both stroke parent and other elderly parent at the same time, they feel collapse and willing to stop in caring.

For emotional impact, family caregivers suffered depression, confinement, loneliness and dispiriting because of long time caring at home. In addition, the family caregivers suffer inferiority because family becomes poor socioeconomic status and they cannot participate in social events. Furthermore, the family caregivers feel worry to leave the stroke patients at home alone or with other family members. As they spend at home for long time in caring, they find way to escape such as willing to run away or willing to suicide. In one hand, some family caregivers are afraid of losing the stroke patients especially stroke parents because alive of stroke parents and living with them give feeling of safe and strength to daughter family caregivers. On the other hand, some family caregivers want the stroke patients to escape from suffering because they do not want to see the stroke patients with pain and suffering for long time.

In social services part, it mainly discuss about the perception of family caregivers in available health care services in public provided by government and private sectors. The family caregivers who utilize the private health care services experience family financial hardship because stroke is long term disability disease and the cost of treatment is expensive. When the family caregivers utilize the public health care services, they feel physical and emotional tiredness because they experience poor

health care services such as long waiting for getting treatment. In addition, as the family caregivers do not receive the health care knowledge for caring of stroke patients, this lack of health care knowledge adds them as a tiredness or burden in caring process.

5.1.2 Family System

Family is a small single unit in society and each family member tries to harmonize the family not to be broken. According to constructed family structure, each family member has been set up roles within a family such as fathers take provider role to support the family financial and mothers perform reproductive role or main homemakers. Both of them hold different power and authority in a family. When a family faces suffering of one family member stroke, other family members need to take care of that stroke patient for long time. When family decides to choose the family caregivers, they think about the religious of point of view or modesty because they are Buddhism. It is highly likely that caring men stroke patients by men family caregivers or women stroke patients by women caregivers because of sensitive in cleaning of sex organ of stroke patients. Furthermore, single, jobless and living same house with stroke patients take more responsibility than other family members within the family.

To compare with men and women, mainly female caregivers take caring of stroke patient role within a family. Therefore, if the family caregivers are married ones, they have to perform a lot of roles like caring, doing housework, childrearing and working at the same time. However, they cannot perform all roles and they have to lose a role such as working or childrearing or doing housework. If the family caregivers perform less or lack in working role, it affects the financial part. Some married caregivers try to do all roles and they feel burnout. Thus, other family members support the family caregivers by sharing their roles to balance the family.

Hence, if the family caregivers have good and clear relationship with family and relatives, they receive more support and reduce the burdens in caring of stroke patients. In fact, as the married family caregivers especially women take lots of roles in family, some family caregivers in the study experience family broken or divorced because other family members especially partner does not share the tasks or does not understand the role of caregivers.

5.1.3 Family Beliefs System

Although family caregivers are difficult to balance or harmonize the family alone and they feel burdens in caring of stroke patients for long time, family beliefs system mitigate the burdens of family caregivers. The burdens reduce because they think that stroke patient is one of family members. In that sense, family caregivers believe that family means combination of single unit by sharing sadness and happiness each other. Therefore, family caregivers take care of the stroke patients for long time with love without saying any grumble.

As the family caregivers take care of their mother or father stroke patients because they respect their parents. So, they do not feel any regret by giving the best care when the stroke parents passed away. The family caregivers think that this kind of taking care is like the repay the debt of parents or family duty. For the relationship of couples between stroke patients and family caregivers, caring is like marriage commitment and the family caregivers take care of the stroke spouse for long time because of their attachment.

All family caregivers take care of stroke patients without leaving or without saying grumble because religion and ancestor teach them at their young age like caring the elderly people or chronic family members is family duty. Moreover, people from environment or relatives in the community are one reason of caring the stroke patients by family. If the family or family caregivers leave the stroke patients without taking care well, people from environment blame that family and say sarcastic.

Not only the outside things force the family caregivers to take care of the stroke patients but also inside things force them to take care. As the family caregivers think that stroke patient is one family member, they try to give the stroke patients the best care. Thus, the family caregivers believe themselves they are more patience and kind to compare with other family members. By taking care of the stroke patients by family, they believe that stroke patients receive warm, love, kind and good care. As a result, the stroke patients feel strong and do not feel stress by receiving care of family members.

On the other hand, almost all of family caregivers are Buddhism and they believe in 'karma'. As they believe in 'karma', caring the stroke patients for long time and suffering some kinds of burdens are their bad karma. The family caregivers think

that they did the bad things the stroke patients in the past life. So, they suffer the burdens and they have to pay that bad karma till the end in the present life. Hence, if the family caregivers take care of the stroke patients well, they will get good karma or merit in the future or next life. If they take care of the stroke patients bad, they will receive bad karma or demerit or going to hell.

In addition, by looking at the perception of stroke disease, the family caregivers believe stroke is bad karma disease because stroke patients did bad things in the past time or past life such as killing the animals. Moreover, stroke is chronic disable disease by giving the family members to feel burnout and financial burden. The last thing of perception of stroke disease is it is less pain disease to compare with cancer because stroke patients can live longer without feeling pain.

Concerning about the perception of cause of stroke, family caregivers think that stroke is mainly cause by hypertension. However, some family caregivers think that stroke is caused by stroke patients' careless action such as stopping medication for hypertension or drinking alcohol. In addition, they also blame doctors because doctors did not give advice to take proper treatment. Some blame themselves because their careless care and action such as staying away with stroke patients that time causes suffering stroke. Finally, stroke is caused by eating salty foods and bathing under too hot or too cold weather.

5.1.4 Coping ways

Both the family beliefs system and coping ways help to reduce the burdens of family caregivers in taking care of stroke patients for long term. For the behavior coping, the family caregivers try to care health than before and take medicine before sick because anyone in family cannot compensate their role. They also do recreational activities to reduce physical and emotional tired. They also try to wear to be good looking because they want to show the other family members like they are strong. They do the tasks non-stop because they do not want to get time for thinking and worry about future.

For the social coping, they try to visit the family and friends houses and also try to participate in social events such as school gathering. They try to call and chat with

friends to reduce the social isolation. For emotional coping, the family caregivers try to do religious stuffs by praying, donation flowers or foods to God, Sabbath and rosary. In addition, they think positively like stroke is common disease and every family suffers similar situation like them. Finally, the family caregivers do auto-self-suggestion like the caring tasks and doing housework is done by them and they are main persons in the family.

5.2 Discussion

5.2.1 Family conflict about taking caring responsibility

Family is a basic social unit and individual tries to perform their own tasks to harmonize the family and not to lead the family broken. Without understanding and sharing tasks among family members, that family leads to family broken. In fact, in this study, one of family caregivers experiences divorce because her husband does not share the caregiver tasks and does not understand the caregiving role. During the conflict time, the family caregiver feels collapse a lot and her acting is not safe for stroke patient.

“My husband is so jealous. If I ask help to driver or even monks, he is always jealous. He creates problems after drinking alcohol. I fight with him. When I feel confused without going out for long time, I locked mom alone at home and visit to my friend. After I told my feeling and condition, I cried a lot because of sadness.”

When that family caregiver has to decide to choose one between stroke mother and husband, she chose stroke mother. She think that

“I can't leave mom. Speaking openly, I can't follow and live with my husband. Parents can't compensate anything in the world, husband can substitute.”

However, after she divorced, all family duties shoulder on her such as doing housework, working, nurturing and taking care of stroke patients. In addition, she has to take full responsibility in nurturing role of her two sons. So, it is difficult to perform all tasks alone without getting other family members support. Unfortunately, she is the only daughter and she does not receive any support from other family members.

“I do not any contact with relatives. Because although I help them by financial support, they didn't help me even physically. I have good relation with my

friends. They made me reducing emotional stress. I feel strangers like housemaids are more helpful than my relatives.”

Although this kind of family separation is obvious, other small disagreements or arguments are occurred concern with allocation caring task. This thing happens among siblings who take care stroke parents because they think that all children have same responsibility to take care of stroke parent. Tin said that

“All siblings need to work equally. Youngest brother wants to influence because he thinks he supports money for mother. I do not accept whenever he says to me. If I think it is not fair, I told him back. Other siblings come and visit to mother is for a while. I have to take care mother full time.”

Therefore, depending upon types of relationship, perception on degree of responsibility is different. The family caregivers who take care stroke parent and have many other siblings perceive that other siblings have same responsibility to take care of stroke parent. If they do not receive support from other siblings, they create small family conflict even not leading to family separation. Thus, family caregivers who take care the stroke spouse and who are only child for stroke parent feel less burdens than caregivers with lots of siblings. They think that they are the most responsible person to take care of stroke patient.

5.2.2 Different types of burdens and copings depending on each caregiver’s specific characteristics

In this study, each family caregiver comes from different family backgrounds and different own characteristics. According to different gender, marital status, socioeconomic status and education, family arrangement in caregiving role, perception on burdens and coping ways are also different.

By looking at the difference degree of taking roles in family based on gender, socioeconomic status and marital status, perception on burdens and coping ways are also different. As mentioned above in finding part, women take main caring role within a family. As women have to handle many roles such as caring role, doing house work, working and nurturing kids at the same time, they feel more burdens than men caregivers.

To compare with single and married caregivers, married caregivers have to take more roles like nurturing the kids and performing husband tasks than single ones, they feel more burdens than single. Among married caregivers, caregivers who take care stroke husbands feel more burdens than caregivers who take care stroke parent. As the husband or main financial provider suffers stroke, they have to perform as a breadwinner instead of husband. At the same time, they have to perform doing house work and nurturing kids besides working out.

Moreover, the main reason of why the male take caring role in this research is there is no women living in the same house. The male family caregivers usually live with sons and brothers together. In addition, due to the rest of family members are working out and the male family caregivers are usually jobless or working less paid job or retired, they occupy the caring role within a family. However, the male family caregivers receive more support than other family members such as bathing, feeding, toileting and dressing because they are male caregivers and other family caregivers who live in the same house or live separate house help them. As a result, Myanmar people accept division of role setting in family such as taking caring role is women. For this perception, the male caregivers receive more support than female caregivers in caring tasks.

Interestingly, although male caregivers perceive that they feel burdens in social parts because they have not travelled and gone out for long time, female caregivers suffer burdens physically because of taking a lot of roles at the same time. Therefore, the male caregivers perceive that they feel more in social burdens and female feel in physical burdens. When looking at coping ways, male and female family caregivers use different coping ways. The male family caregivers try to do more in social coping such as visiting to the friends or relatives or travelling. However, female caregivers try to do in emotional coping such as doing religious things at home or praying. As a result, female caregivers do not receive enough physical support from other family members and they try to cope burdens with emotional way whereas they suffer more burdens in physical part.

In addition, due to different socioeconomic status, the degree of caring responsibility and suffering of burdens are different too. Whereas caregivers from poor socioeconomic status have to perform a lot of role such as the working, doing house

work and caring, some family caregivers from high socioeconomic take less role. If they work out, they leave the stroke patients with nurse or paid caregivers. Some also hire house maid for doing house work. Moreover, family caregivers from poor socioeconomic status receive lack or less support especially financial and physical support from other family members because other family members have to struggle for their living of own families. Thus, family caregivers from poor socioeconomic status suffer more burdens because of lack or less of family support.

Furthermore, the perception on burdens are different between poor and high socioeconomic status. The family caregivers from poor socioeconomic status feel happier and more satisfied than caregivers from high income family. The main reason is their requirement is simple and they want to get basic requirements such as repairing the house and mending the hole of house. The family caregivers from high socioeconomic status also possess high education level at the same time. They feel that they lose their own life and future personal development such as quitting the job, loss of opportunity to get job in young age. For these reasons, they do not feel as happier as family caregivers from poor socioeconomic status.

In addition, to compare the coping ways between high and low socioeconomic statuses, the family caregivers from high socioeconomic status use social coping way especially visiting and communication to the friends or relatives and participating in social events. By looking at their physical coping, mostly they do exercise and do recreational activities such as watching movies and listening to the music. But, family caregivers from poor socioeconomic status try to cope mainly physical way. As they are poor and no one cannot compensate their role within a family when they are sick, they try to take medicine before sick or do the tasks non-stop without giving time to think of sad past time.

5.2.3 Meaning of caregiving

This study reveals the connection between family beliefs system and burdens of family caregivers in taking care of stroke patients. Religion and family culture appears to influence family caregivers directly. Finding shows that there are five major themes which are caregiving is burdens, caregiving is karma, caregiving is family

moral value, caregiving is family core value and caregiving is living adaptation and receiving support.

5.2.3.1 Caregiving is burdens

The previous study of Sethabouppha, H., & Kane, C. (2005) point out that caregiving is suffering because family caregivers suffer physical burden, emotional distress, economic problems, social problems and knowledge deficit. The family caregivers have to sell some assets such as house, gold, cars, pigs, cows and all valuable things at home and at the end they live in debt for the cost of living and treatment of stroke patients. This finding is consistent with previous study of Nguyen, T.T.C. (2009). As stroke is long-term chronic disability disease, it creates financial difficulties. As a result, not only stroke patients but also family caregivers do not get proper treatment.

According to Anantato (2005 p-102 &103), family caregivers do not get proper treatment because of spending all money for the treatment of stroke patients. Besides family financial difficulties for taking treatment of stroke patients, the finding of this study indicates that family caregivers also do not get proper treatment because they do not have enough time to take treatment and any one in family cannot compensate their caregiving role during hospitalized time. In addition, Nguyen, T.T.C. (2009) showed that family members experience difficult to pay children education and hard to do family plans like cancelling wedding of family member because of stroke. But, some family members of participants in this study experience quit the school and live in an old damage house.

Furthermore, in social burden part, family caregivers experience less or lack personal time, outing and travelling and less or lack participation in social events. At the end, they feel loneliness and living at home for long time by caring is like a prison. These kind of social burdens are same findings of recent studies which were conducted by Alnazly, E.K. & Samara, N. A., (2014) and Thommenssen, B.et.al (2002).

In the physical impact, the family caregivers suffer sleeplessness, tired, loss weight and headaches. Alnazly, E.K & Samara, N. A., (2014) pointed out that the family caregivers suffer body ache and joint pain because of carrying the stroke patients for daily activities for long time. It is interestingly that only female caregivers suffer arm pain and body pain in this study. In addition, among family caregivers, the

elderly family caregivers experience difficulties in caring process because of old aged and suffering some kinds of diseases.

There is same finding with Nguyen, T.T.C. (2009) and Rittman, M. et.al (2009) for emotional part. The family caregivers feel worry, depressed and sad because of long term care and looking the loved family member's disability and suffering. Besides depressed, the family caregivers in this study experience inferiority because stroke disease makes them poor socioeconomic status and family caregivers do not want to participate in social events then. As some family caregivers feel collapse and financial difficulties, they want to run away from caring and have willingness to suicide during difficult time. Finally, the family caregivers do not receive enough health care knowledge and they want to get health care training from health care professions. That knowledge deficit leads them to feel burden.

5.2.3.2 Caregiving is karma

Due to stroke is a chronic disable disease and stroke patients need the family caregivers to do their daily activities for long term, family caregiving is a difficult and lead the family caregivers to suffer burdens. Although they suffer burdens, they endure the hard caregiving work and continue it because of karma. According to Carone, Jr, D.A. & Barone, D.F. (2001), people who believe in religion involve in external locus of control by powerful others because they believe in god. When people encounter many hardships in their life, religion supports them to show the ways of coping and way of positive thinking and act.

When looking at cultural context of Myanmar, religion takes a powerful role to shape burdens of family caregivers in taking care of stroke patients. Most people in Myanmar are Buddhism and they are strongly believe in karma. In addition, almost all of family caregivers in this study are also Buddhism and this belief mitigate the burdens. The family caregivers in this study take caregiving role and suffer the burdens because of bad karma. As they did the bad things in the past lives, they have to pay it back in the present lives till the bad karma end. In the present situation, if they take care well, they will receive merit or good karma. That good karma will support them to possess happy and peaceful life in the future or in the next lives. If they take care badly such as scolding or shouting the patients, they will receive demerit or sin or

bad karma or going to hell. Furthermore, if they abandon the patients without taking any responsibility or if they treat badly during care, they will suffer same things what they act to the patients in the future. This study is similar to three previous study in Thailand and Taiwan where majority of religion is Buddhism (Sethabouppha, H. & Kane, C., (2005), Subgranon, R. & Lund, D.A., (2000) and Hsu, H. C. & Shyu, Y-I. L., (2003).

Therefore, karma is a way of coping or self -consolation with the caregiving burdens and it supports the family caregivers to accept the caregiving role. Because of karma, family caregivers do not complain the burdens and they try to take care the stroke patients with the best care (H. C. & Shyu, Y-I. L., 2003). As a result, karma drives the family caregivers to continue taking care of stroke patients for long time even they feel burdens.

5.2.3.3 Caregiving is family moral value

In the research finding, family caregivers take care of the stroke patients due to family duty or responsibility, seniority, repay the debt of parents and marriage commitment. Caregiving is family duty because family members do not trust outsiders to take care of elderly relatives. This is one reason of caring by family members and this finding is similar with previous research (Subgranon, R. & Lund, D.A., 2000). Besides worrying about the quality of care by outsiders, the family caregivers in this study prefer to take care of the stroke patients by themselves because the stroke patients can receive love, kindness and patient care from the family members.

Moreover, the family caregivers who take care of their parents perceive that caring the parents is a kind of repay the debt of parents. For spouses relationship, caring is based on marriage commitment. Hsu, H. C. & Shyu, Y-I. L., (2003) discussed that family duty or family obligation and repay the debt of parents are not a reason of caring. This bridge as mediator to motivate the family caregivers to take care and these help the caregivers to cope with their burdens. In addition, beliefs on family obligation or marriage commitment or repay the debt of parents in taking care of stroke patients process pull the family caregivers continuation of care for long time.

In fact, the belief of family obligation to care for stroke patients is strengthened by public opinion. In this study, family caregivers accept social appreciation or criticism from neighbors or relatives upon taking care of stroke patients for long time or leaving the stroke patients without taking caring responsibility. This

finding is same with Hsu, H. C. & Shyu, Y-I. L., (2003) finding. The former researchers discuss that public opinion is not motivation the family caregivers for family care. It just pushes the family caregivers to continue of care.

5.2.3.4 Caregiving is family core value

A family is built as a single unit to be a happy and unity family by sharing tasks within the family. Each family member shares sadness and happiness each other and helps each other by filling one's needs to another. According to Subgranon, R. & Lund, D.A., (2000), love among family members is created by blood relationship closeness between parents and children and by time spend together and goodness shared with each other between spouses. In this study, family caregivers take care of the stroke patients for long time because of love and respect. They take care of the stroke patients for long time because they love family and stroke patient is one of family members. In addition, family caregivers take care of the patients because of attachment, love and sympathy (Sethabouppha, H. & Kane, C., 2005). In fact, affection and attachment make the family caregivers to feel continuation of care. Moreover, this affection perform as intermediary factor to help caregivers in coping the burdens and it also influences to continue of caring process (Hsu, H. C. & Shyu, Y-I. L., 2003).

Furthermore, family caregivers take care the stroke patients because of sense of family duty and affection. It is interestingly that family beliefs are similar whereas family caregivers are from different gender, age and socioeconomic status in this study. However, according to Montgomery (1996), the sense of family duty and taking responsibility in caring is less because of weak of moral value. This kind of less moral value depends upon gender, generation, ethnicity and social class. As a result, in the future, the family beliefs in Myanmar can change to weak moral value when passing from generation to generation.

5.2.3.5 Caregiving is living adaptation and receiving support

When the family caregivers take care the stroke patients for long time with less or lack of family support, they feel burdens. At the same time, they try to cope burdens with three ways; behavior coping, social coping and emotional coping. They take care of their health than before, do recreational activities and take medicines before sick because anyone in family cannot compensate their roles. Moreover, they do

visiting to friends and relatives, think positively and do religious practice for social and emotional coping. That means that they try to adapt with the condition of family situation, degree of disease and patients situation. According to Sethabouppha, H. & Kane, C., (2005), these kinds of coping or living adaptations create mediator to relieve stress during care the ill family members for long time.

Moreover, getting financial, physical, emotional and social support by family members in caring process is consistent with previous study (Sethabouppha, H. & Kane, C., 2005). However, the previous study shows that extended family is the major support to family caregivers. In this research, the family caregivers who descend from extended families more receive family support than caregivers from nuclear families. Therefore, family caregivers who are from nuclear families suffer more difficulties or burdens in caring of stroke patients. In addition, the family types in Mandalay are more likely to have the nuclear family types in the future. As a result, taking caregiving roles by family is difficult in the near future in Mandalay, Myanmar. According to Hsu, H. C. & Shyu, Y-I. L., (2003), traditional family caregiving in Taiwan is not able to held for long time because of competing family responsibility, increased burdens in care and modern social welfare system.

Hence, the family caregivers in this study receive not only support from other family members but also from neighbors and friends in community. They receive support such as visit, money, food, advice and temporary care. This finding is consistent with Sethabouppha, H. & Kane, C., (2005) and Subgranon, R. & Lund, D.A., (2000). But, in this research finding, the family caregivers from poor socioeconomic status are hard to receive support especially physical and financial supports from other family members and neighbors because they are also come from poor socioeconomic status and have to work out full time for their own families. As a result, the family caregivers who come from poor socioeconomic status experience more burdens than other because of less or lack of support from other family members and neighbors.

In conclusion, the family caregivers who take care of the stroke patients experience difficulties in caring because of less or lack support of financial, emotional, physical and social aspects by family. In addition, less support of health care knowledge and financial by government add the family caregivers to feel burdens in

caring process. Hence, due to lack of social welfare of caregivers payment and disability support pension in Myanmar, the family caregivers who take care for stroke patients for long time are facing financial difficulties.

Furthermore, less or lack number of other family members who can compensate the caregiving role instead of family caregivers and long-time caring of stroke patients force the family caregivers to feel collapse. As a result, the family caregivers in this study perceive that they suffer some types of burdens or face difficulties in caring process by themselves.

Hence, the family beliefs such as beliefs in karma, family moral value and family core value are strongly influence on perception of family caregivers in caring process for long time. Basically, the family caregivers can continue the caring of stroke patients for long time because of above main three beliefs. These beliefs make the family caregivers to accept the caregiving roles, not complain burdens and give the best care to stroke patients.

Generally, all family caregivers put their money, efforts and personal time in caring of stroke patients. The sense of self-willingness of taking caring responsibility could not be same all of them whereas three kinds of beliefs drive the family caregivers to continue the caregiving.

When the family caregivers have much sense in afraid of getting demerit or sin or bad karma or going to hell, the self-willingness of caring tilt to low level because karma control the desire of caring responsibility. However, the family caregivers who expect merit or good karma include in high self-willingness of caring responsibility. Although these kinds of family caregivers are under control of karma, their desire to care is high because they expect to get good things in the future.

In addition, the self-willingness of taking caring responsibility incline low level when the family caregivers who strongly believe in family moral value such as family duty, repay the debt of parents or marriage commitment. Moreover, the family caregivers who care about the public opinion such as afraid of sarcasm in caring of stroke patients by relatives, friends or neighbors are also lean to low self-willingness of taking responsibility. As family obligation and moral values bond strongly these

kinds of family caregivers, their self-willingness of caring responsibility is not becoming free desires of caring.

On the other hand, as the family caregivers take care of the stroke patients with family strong attachment and affection such as love, respect and sympathy, their self-willingness of caring responsibility is high. These family attachment and affection are higher desire of caring responsibility than family obligation. To sum up, some family caregivers have much sense in high self-willingness in caring responsibility while others are in low self-willingness in this research. On the other hand, some sense both in taking care of stroke patients at the same time.

5.3 Recommendation

5.3.1 Policy recommendation

Among the family caregivers, elderly caregivers and caregivers from poor socioeconomic status suffer more burdens than other groups. Therefore, for these populations, government needs to set up brief situation policy priority setting such as financial support, health care services support and educational support.

Social security system is improved and that provides caregivers payment and disability support pension to stroke patients and family caregivers. By providing money to the stroke patients and family caregivers by government, they can fill the basic needs such as foods, clothing, housing, education and medical care within the family. Not only money but also required equipment such as wheelchair, postural tilt bed, crutches or other equipment needed for caring of stroke patients are provided to get essential medical care and treatment at home.

Home health care services are supported by the visiting nurses or health care professions regularly. They visit the stroke patients' houses and give treatment with free of charges or cheap cost of treatment. In addition, by opening emergency call center, not only stroke patients but also family caregivers can access health care services easily during important cases and conditions. Further, phone call health services are fast and effective health care in community especially for people who are living in suburb areas, difficult for transportation or difficult for moving or travelling.

By setting up the caregivers' education programs or campaigns in the community, these campaigns recruited young people who can take care of the stroke patients as volunteer work. The family members or relatives of stroke patients also participate that kind of caring education programs. The health care professionals such as doctors, nurses, physical therapists or social workers give training these people how to take care the patients till getting qualify caregivers. Not only providing training but also monitoring is essential such as the caregivers take care the stroke patients with right way or not.

The education programs and campaigns are advertised in public via media or television programs such as ways of taking care of stroke patients or address of organizations which can support home-based care. Another way of giving information about stroke is publishing books or pamphlets which direct the caregivers how to take care of stroke patients. The national organizations like public hospitals provide these kind of support before discharge the stroke patients to home with free of charge. Moreover, the family caregivers can attend online training of ways of caring of stoke patients at home. The online education program is useful for family caregivers who cannot leave the stroke patients at home alone.

However, Myanmar is a developing country and the capacity of filling the requirements of poor socioeconomic status of stroke patients and family caregivers are limited because of limited infrastructure and resources. Therefore, these polices could not set up at the same time and can set up step by step to improve the quality of life of stroke patients and family caregivers. Finally, co-operation among family caregivers, government, policy makers, mass media, health care professions and social workers at both community and national levels is important to achieve the goals of protection of human health.

5.3.2 Recommendation for further research

Firstly, Mandalay is better infrastructure and the best health care accessibility in upper Myanmar. The findings and results in research site of Mandalay are different from in rural area in Myanmar because of different health care accessibility

and infrastructure. Therefore, conducting this kind of study in other rural area of Myanmar can compare with it.

Secondly, this study focuses on beliefs and perception of caregiving roles from the view of family caregivers. Hence, some caregivers receive support from the other family members, but, some do not receive any help or receive little help from the family members. As a result, family caregivers feel burnout because caring of stroke patients is long. Thus, for the understanding the perception on burdens and beliefs of caring roles, family members, neighbors and friends can be added as the participants.

Thirdly, in this study, the stroke illness phase such as initial crisis, chronic and terminal stages have different types and degree of burdens. These phases also influence the beliefs or perception of caregivers in caring of stroke patients. Here, all things are expressed as general and not in detail. Therefore, to understand deeply the perception and burdens of family caregivers in caring of stroke patients, the comparative study among three phases gain rich information.

Fourthly, the number of family size shrinks in Mandalay. Although some families are extended family type, the number of family is small. In addition, in the study of most cases, the elderly family caregivers have to take care of the stroke patients and they feel more burdens. The recommended further research is that focusing on the burdens of elderly caregivers in taking care of chronic diseases including stroke should be conducted to set up the effective policy for both chronic patients and elderly family caregivers.

Fifthly, stroke patients can access health care services mainly three sectors which are private western hospital, public western hospital and traditional medicines and massages. However, in this study, most stroke patients do not get proper treatment because stroke is a long-term chronic disease. Therefore, cost-effectiveness analysis can inform decision makers to improve the effective health care services of stroke patients.

Finally, individual performs their own tasks to harmonize the family which descending from family system. Family system theory emphasize to balance the family that not leading the family broken. Overall, the family caregivers and other family members hold the family belief to harmonize the family by doing their own functions in caring process. However, caring of stroke patients is long term and family caregivers and other family members can experience small conflicts or disagreements during daily

care. This is one of limitations of family system theory. Therefore, for next research, it should be pay attention to conflict and negotiation among family caregivers, stroke patients and other family members.

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APPENDICES

Appendix A
IN-DEPTH INTERVIEW AND KEY INFORMANT INTERVIEW
GUIDELINE FOR FAMILY CAREGIVERS AND FAMILY
MEMBERS OR STROKE PATIENTS

Topic	Questions	Informants
Characteristics of family	<ol style="list-style-type: none"> 1. Number of family members and Siblings 2. Could you please share me about meaning of family? 3. Are there any family members who suffered stroke before? If have please share me about it? 4. How do you contact with other family members? 	Caregivers, family members or stroke patients
Characteristics of stroke disease	<ol style="list-style-type: none"> 1. Could you please tell me about the stroke patients during admitted day of hospital? 2. Could you please share me about nature of stroke? 3. Now what treatment does the family patient need? 4. What cause the stroke patient leading to illness? How the illness will be better? 	Caregivers, family members or stroke patients
Characteristics of caregivers	<ol style="list-style-type: none"> 1. Name, age, sex, marital status, occupation and education 2. Please tell me about daily activities before and during taking care of stroke patients? 3. What kind of changes did the family caregivers face in the daily life activities before and during taking care of stroke patients? 4. Explain about the experience of taking care about the illness before stroke, during taking treatment and at home 	Caregivers, family members or stroke patients

Family beliefs system and coping ways	<ol style="list-style-type: none"> 1. Could you please share me about the view of caring for stroke patients? 2. What things make the family caregivers in taking care of stroke patients? 3. Why do the family caregivers take care of stroke patients? 4. What do the family caregivers think about in caring role of stroke patients? 5. What factors (thinking) make the family caregivers strength to take care of stroke patients? 6. What the family caregivers think and feel about the getting support from the family members? 7. If the family caregivers do not receive the helpful support or no support from family, why the family caregivers cannot get help from other family members? 	Caregivers
Perception on burdens and coping ways	<ol style="list-style-type: none"> 1. What problems do the family caregivers face in caring? 2. Please tell me about feeling and thinking of caring on stroke patients now 3. Could you please share me any worries about caring 4. If the family caregivers feel tired or stop taking care of stroke patients, what the caregivers do? Why? 5. Please tell about the most willing that the family caregivers want to do and want to have 	Caregivers
View on caring of family caregives	<ol style="list-style-type: none"> 1. Could you please share about the view of caring of stroke patients? 2. What the family caregivers usually do daily? 3. What kind of tasks do you help the family caregivers? 4. Could you please share about feeling and thinking about responsibility and role of caregivers? 	Family members or stroke patients

	<p>5. How does the family share tasks of caring?</p> <p>6. If the family member's view is different from caregivers, how do both make decision?</p> <p>7. What do the family members think about the caring of family caregivers?</p> <p>8. If the family member take role of caregiving instead of family caregivers, could the family member take role of caregiving?</p>	
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Appendix B

OBSERVATION GUIDELINES

1. How the family relation and communication of family during interviewing process? (talk friendly each other, help caring of stroke patients during interviewing process,
2. How is the family caregivers' physical appearance? (sleepy, tired or clothing wearing neat and tidy)
3. How is the condition of stroke patients? (hygiene, clean bed sheet, having bed sores, swelling of legs or arms, stiffness or deformity of arms or legs)

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