

Stroke Caregiving Networks in Bangkok: Patterns of Social Exchange Behavior

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Abstract: This exploratory, descriptive, ethnographic study of 22 primary caregivers and 20 non-primary caregivers, who comprised 18 caregiving networks, sought to describe stroke caregiving networks and patterns of caregivers' social exchange behaviors that influenced stroke caregiving. The concept of social network, in conjunction with social exchange theory, was used to describe relationships within the caregiving networks. Data were collected, January-September 2008, through a demographic data sheet, in-depth interviews and observations, household assessment, geographic mapping and network analysis. Data analyses were carried out via descriptive statistics and context analysis, using the method outlined by Lecompte and Schensul.

The findings revealed factors associated with the caregiving networks were: size (structural); communication (informational); duration and time (social); finances (financial); and, relationships and satisfaction (psychological). In addition, three major patterns of social exchange behavior were noted: (a) sharing care, in which care functions were divided among the primary caregiver and non-primary caregivers; (b) dual care, wherein care functions were delivered by two primary caregivers, along with non-primary caregivers; and, (c) supplementary care, whereby the primary caregiver, often a spouse, performed caregiving alone or with occasional support from non-primary caregivers.

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Introduction

Stroke has been recognized, in Thailand, as the leading cause of disease burden among women, and the fourth cause of disease burden among men.¹ Due to impairments of cognition, communication and activities, some stroke victims require assistance or need total care from others.²

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Although previous studies have revealed the tasks caregivers perform in providing care for stroke victims and how networking (linking individuals to a social system) can positively and/or negatively affect the outcome of caregiving for stroke patients,^{3,4} little is known about how members of stroke caregiving networks engage in social exchange behaviors. A caregiving network consists of individuals (primary care givers and non-primary caregivers) who provide stroke care and exchange caregiving behaviors with each other. The primary caregivers generally are members of the stroke victim's family, who are continually in charge of providing care for the patient.⁵ On the other hand, the caregiving network members (non-primary caregivers) are both family members and individuals (associated with specific organizations that focus on stroke care) who provide support so the primary caregivers can maintain their caregiving roles.⁶

While prior studies have provided understanding about family caregiving for stroke patients in rural and small cities,^{7,8} a limited number of investigations have been undertaken regarding caregiving within large urban areas.⁹ No studies, in English or Thai, could be located with respect to social exchange behaviors within stroke caregiving networks in Thailand.

The cost of living in Bangkok, a major urban area of Thailand, has lead, unlike other Thai provinces, to an increase in childless marriages and a decrease in family size.¹⁰ Thus, fewer family members are available to provide required care for ill family members. This has lead to the formation of caregiving networks through which families can obtain other individuals to assist in the provision of care for their ill family members.¹¹ Prior studies have shown changes within caregiving networks in terms of: their familial, social and cultural contexts; the caregivers' abilities and resources; and, the care burden.¹²

Conceptual Framework and Review of Literature

The concept of social networks (a system or web of relationships linking one or more specific type of relationships in terms of persons, objects and events)¹³ was used to describe the individuals and their relationships within the stroke caregiving networks. Characteristics of a social network include linkages and members' attributes that can be analyzed through identified structures, interactions and members within the network.

Social exchange theory,¹⁴ which describes the social or cultural rules for understanding how individuals aggregate with others, was used as the conceptual framework upon which to investigate the patterns of social exchange behaviors within stroke caregiving networks. Social exchange theory has been used to explore caregiving behaviors in terms of exchange relations and consists of three theoretical frameworks. These include: equity theory; resource theory; and, theory of indebtedness. Equity theory addresses balanced and imbalanced relationships. On the other hand, resource theory, which has positive and negative outcomes, speaks to the relationship between giving and taking. The theory of indebtedness focuses on what has been received or provided in the past. Thus, social exchange theory provides a framework for understandings the dynamic process of stroke caregiving.

Caregiving experiences and outcomes often vary among different racial and ethnic groups. For example, caregiving may be considered a woman's role among some groups,¹⁵ while Chinese,¹⁶ Japanese,¹⁷ Korean¹⁸ and Thai¹⁹ elders often expect needed caregiving to be provided by their children. However, within the Thai culture, a significant characteristic of the agrarian work pattern is interdependence and interactive relationships among community members.

In addition, caregiving within Thai families is based on the living arrangements, roles and responsibilities of those involved in providing care.²⁰ Specifically, stroke caregiving, in Thailand, is known to be shaped based on the: individuals' and caregivers' cultural and religious backgrounds;⁸ caregiver roles;⁴ living arrangements;⁷ and, traditional beliefs about stroke care.²¹ Given the limited information regarding how members of stroke caregiving networks exchange their caregiving behaviors, this study sought to explore and describe stroke caregiving networks and patterns of caregivers' social exchange behaviors that influenced stroke caregiving.

Method

Design: This exploratory, descriptive, ethnographic study sought to describe and explore the social exchange behaviors within 18 stroke caregiving networks comprised of 22 primary family caregivers and 20 non-primary caregivers in Bangkok, Thailand. Ethnography was chosen as a means to achieve these aims because contemporary ethnography focuses on a particular aspect or dimension.²²

Ethical Considerations: The research protocol was approved by the Institutional Review Boards (IRB) of Ramathibodi Hospital and the Neurological Institute, prior to initiation of the fieldwork. Before asking each potential participant of a stroke caregiving network to take part in the study, the primary investigator (PI) explained the: purpose of the study; data gathering process; benefits/risks of the study; issues regarding confidentiality and anonymity; and, right to withdraw from the study without repercussions. All potential participants consenting to take part in the study were asked to sign a consent form. As a thank you, each participant received a small token of appreciation.

Participants: Names of potential participants were obtained through the assistance of home health care nurses at Ramathibodi Hospital and the

Neurological Institute, and the Directors and health care volunteers at two Community Health Care Centers under the administration of Ramathibodi Hospital. The criteria for selection of members of the stroke caregiving network (primary caregivers and non-primary care givers) included those who: had provided care, for the last two months, to a stroke victim, 60 years of age or older, with a score of 0 to 20 on a modified version of the Barthel Index;²³ lived in the same household or same household area as the stroke victim; was able to understand, speak, read and write Thai; was not paid as a caregiver by an agency; and, was willing to participate in the study. Those who were being paid by an agency were excluded due to the fact they were likely to have social support relationships and mechanisms of giving and taking (social exchange behavior) different from caregivers who were not paid.

A total of 42 participants, who were part of 18 caregiving networks, were contacted to take part in the study. Of these participants, 22 were primary caregivers and 20 were non-primary caregivers. Of the caregiving network, 6 were from Ramathibodi hospital, 6 were from the Neurological Institute and 6 were from the two community health centers. Among the caregiving networks, 14 of the stroke victims had one primary caregiver, while 4 had two primary caregivers.

Among the 22 primary caregivers, 11 were married, six were single and five were widowed. They ranged in age from 28–75 years (average = 52 years) and consisted of 19 females and three males, including eleven daughters, six wives, two sons, one daughter in – Law, one brother and one niece of the stroke victims. Nineteen of the primary caregivers were Buddhists and three were Muslims who had provided care for 4 months – 20 years (average = 4 years). They had an income of 1,000 to 10,000 baht per month (average = 4,000 baht per month; 30 baht = \$1USD). Twelve of the primary caregivers worked in addition to providing care. However, ten could not work because

of the demands of caregiving and/or as a result of their underlying illnesses. Eight of the primary caregivers completed primary school, six completed secondary school, three completed vocational school and one had a baccalaureate degree. However, four had no formal education.

The 20 non-primary caregivers, who were 28–60 years of age (average = 41.6 years), consisted of family members, as well as individuals from outside the family. They included 13 daughters, and two nieces of the stroke victims, as well as two health care volunteers, one primary care nurse, one friend and one neighbor. Nineteen were females and one was a male. In addition, ten were single, 16 were Buddhist and four were Muslim. Even though one had no formal education, six of them had a primary education, six completed secondary school, five had vocational schooling, one had a baccalaureate degree and one held a masters degree. Ten of the non-primary caregivers lived in the same household as the primary caregivers, while six lived less than 10 minutes way and four lived more than 10 minutes away.

Instruments: Data were obtained through use of a modified version of the Barthel Index,²³ demographic data sheet, interviews, observations, household assessments, geographic mappings and network analyses. The modified Barthel Index,²³ consisted of ten items that addressed the extent to which an individual could carry out activities of daily living, including: bathing, grooming (brushing teeth, combing hair, shaving and putting on make-up), transferring, moving (walking), feeding, dressing, toilet use, climbing stairs, bladder control and bowel control. The categories of bathing and grooming had possible responses of: 2 = independent; 1 = requires some assistance; and, 0 = completely dependent. The activities of transferring and moving had possible responses of: 6 = independent; 4 = requires less assistance; 2 = requires more assistance; and, 0 = completely dependent. The activities of feeding,

dressing, toilet use and climbing stairs had possible responses of: 4 = independent; 2 = requires some assistance; and, 0 = completely dependent. Finally, the activities of bladder and bowel control had possible responses of: 4 = completely continent; 2 = mostly continent; and, 0 = completely incontinent. Total scores could range from 0 to 40. Individuals with a score between 0 and 20 were considered to require extensive care by the primary and non-primary caregivers.

Demographic information was obtained by way of a *demographic data sheet*. Information obtained on primary caregivers included: age, gender, marital status, presence or absence of a major health care problem, relationship to the stroke victim, length of care provision, education, employment status, and income. Information obtained on non-primary caregivers included: age, gender, marital status, religion, relationship to the stroke victim, place of residence (with or not with stroke victim) and education.

The *interviews and observations* of the primary and non-primary caregivers were guided by an investigator-developed interview protocol. The initial interview questions focused on how the participants came to be caregivers and the type of caregiving activities the participants provided. Examples of the probing questions, used to clarify and obtain additional information, included: (a) “What specific experiences occur during caregiving?”; (b) “Who participates in the various aspects of caregiving (physical, psychological, socio-cultural and spiritual)?”; (c) “What is the quantity and quality of the caregiving provided?”; and, (d) “What difficulties are encountered during caregiving?” After each interview, observations made were immediately recorded in notes. In addition, each interview was tape-recorded.

Geographical mapping was done to determine how long it took the non-primary caregivers to get from their places of residence to the residences of the stroke victims. This process was done by locating, on a map, the stroke victims’ homes and the non-primary

caregivers' homes. The length of travel time for the non-primary caregivers was calculated based upon the distance between the non-primary caregivers' homes and the stroke victims' homes.

Household assessment, of each stroke victim's home, was carried out by observation of the environment within the household and recording of the observations via field notes or photography. For example, photographs were taken of the primary and non-primary caregivers as they worked alone or as a team in the provision of care.

Network analysis was carried out for the purposes of: determining the structure of the caregiving network; understanding the processes of how non-primary caregivers made connections with the stroke victims and their primary caregivers; and, understanding the content, objective and function of each of the caregiving network configurations. Network analysis was conducted by use of nodes and ties.²⁴ Nodes were drawn and numerically labeled to represent a specific member within a network, while ties were drawn to demonstrate the relationships (direct or indirect) among the various nodes (members of the network). In addition, the frequency (occasionally, daily, weekly or monthly) and the content and objective of the various relationships, within each network, were noted and recorded.

Procedure: The home health nurses, directors and health care volunteers of the organizations, used as data gathering sites, were provided with the participant inclusion criteria and asked to identify potential primary and non-primary caregivers of stroke victims. The PI then telephonically contacted the potential participants. During the telephone interview, the PI reviewed the inclusion criteria, including the questions in the modified version of the Barthel Index, to assure the individual met the inclusion criteria. If, during the initial telephone contact, it was determined a potential participant did not meet the inclusion criteria, the PI thanked him/

her for his/her time, and did not invite the person to participate. All potential participants, meeting the inclusion criteria, were invited to take part in the study.

After primary caregiver participants consented to participate, arrangements were made to obtain demographic data and conduct interviews, observations, household assessments and network analyses, at the stroke victims' homes. However, the non-primary caregivers chose where (stroke patients' homes, caregivers' homes, hospital, or community health centers) their demographic data, geographic mapping, interviews and observations were conducted. Data collection took one to three hours per participant. Of the 18 caregiving networks, members of 14 networks were observed and interviewed twice, while members of four networks were interviewed three times. Participants required additional sessions of data retrieval due to the: demands of their caregiving; speed with which data could be obtained; and/or, time they were available. Throughout the data gathering process, issues or problems that arose, regarding the research process, were recorded in field notes for the purpose of making certain they were addressed at a later date.

Data Analysis: Descriptive statistics were used to calculate the Barthel Index scores and analyze demographic data. Qualitative data were analyzed via Lecompte and Schensul's context analysis method, 22 which involved organizing data into various files (document files, field notes, background files and text files). Document files consisted of data obtained from observations, geographic mappings, household assessments and network analyses. Field notes contained data on issues and problems related to the research process, while background files consisted of demographic information. Finally, text files contained the transcribed words of the participants during the interviews. Data from all files were entered into the Nvivo software program in order to determine units, patterns and structures. The analysis proceeded

from the bottom up, by building from items and variables (units) to factors (patterns) and domains (structures).

Trustworthiness of data was established through use of credibility, consistency, neutrality and applicability/transferability.²⁵ Credibility was assured through triangulation and member checking. Consistency was maintained via use of notes and reflexive sessions with participants during data collection. To prevent bias, neutrality was obtained through use of multiple strategies to confirm the findings (observations, interviews, household assessments, geographic mappings and network recordings). Finally, to ensure applicability/transferability, the PI, explicated the setting, sample technique and characteristics of the sample, as well as obtained participants from multiple settings and sites.

Results and Discussion

Description of Stroke Caregiving Networks

The structural factor of size was found to be important within the caregiving networks. Three network sizes were found to be small (4 to 5 members), medium (6 to 7 members) or large (8 to 10 members). Of the 18 caregiving networks, eight (networks #: 1, 3, 4, 5, 9, 16, 17 &18) were small, five (network #: 2, 6, 12, 13 &15) were medium, and five (networks #: 7, 8, 10, 11 &14) were large.

The *informational factor of communication* (direct and indirect) can influence caregiving exchange between the primary caregiver and other members of the caregiving network. Networks that had the best developed forms of communication were found to more effectively stimulate the caregiving network members to participate in caregiving. Networks with less developed forms of communication failed to consistently stimulate caregiving network participation in caregiving. However, within all of the networks, at various points in time, some of the network members failed to effectively communicate among themselves.

The *social factor of time* influences one's availability to engage in caregiving activities. Members of the caregiving networks who had fewer personal and family responsibilities were found to be the ones most involved in providing caregiving. As members of the network, they shared among themselves when they would be available to provide care and for what length of time. The social factor of duration refers to how long one had resided within a given community. Duration can influence to what degree a specific individual, within a community, is willing to participate in caregiving activities. Individuals whose families had resided, for several generations, within the community were found to be more willing to participate in caregiving activities than those who had recently moved into the community.

The *economic factor of finances* played an important part in stroke caregiving in terms of having adequate funds to pay bills and meet the basics needs of self and others. As previously mentioned, 12 of the primary caregivers worked in addition to providing care, while ten could not work because of the demands of caregiving and/or as a result of their underlying illnesses.

The *psychological factor of relationships* related to caregiving exchange influenced the degree to which members of the network engaged in positive or conflict interactions. When the interactions were found to be positive, the caregiving exchanges among the network members were found also to be positive. Finally, the psychological factor of satisfaction influenced how pleasurable the network members found the exchange of caregiving behavior. A number of network members stated their willingness (tem-jai) to participate in caregiving, while others simply talked about their endurance (jum-jai) to participate.

Patterns of Social Exchange Behavior

From the factors of size (structural), communication (informational), duration and time (social), finances (financial), and, relationships

and satisfaction (psychological), three patterns of social exchange behaviors emerged. These patterns

included: sharing care; dual care; and, supplementary care (See **Table 1**).

Table 1 Summary of Patterns of Social Exchange Behaviors

Factors	Sharing care	Dual care	Supplementary care
Size	Primarily large, but some small	Small & medium	Small, medium & large
Composition	Family/community members	Family/ community members	Spouse/family/ community members
Satisfaction	Willingness	Willingness & endurance	Willingness & endurance
Motivation	Internal	Internal & external	External
Time	Set schedule	Set &varied schedule	Schedule when available
Duration	Long & short	Long	Long
Finances	Consistent	Consistent	Consistent &occasional
Communication	Primarily direct	Direct	Direct & indirect
Relationships	Close & conflict	Close & conflict	Primarily conflict
Caregiving Interactions	Supervisor/member	Buddy system	Leader/member
Function	Task specific care	Shared care	Varied care

Sharing care refers to the pattern of network exchange that separates caregiving roles and responsibilities among caregiving network members (individuals and/or groups). In other words, caregiving, among the network members, was delivered under a task specific model²⁶ and carried out, like “cutting a pie into separate piece.” This type of caregiving has been found to be suitable to accommodate individuals’ personal activities.²⁷

Eight of the caregiving networks (#s: 2, 4, 7, 8, 11, 14, 17 & 18) used care sharing patterns. Activities of caring (i.e. preparing a blenderized diet for the stroke victim, doing laundry or bathing the stroke victim) were given to an individual or group depending upon the competency each had for the particular assigned task. The relationships among

the network members often involved a supervisor or “worker bee” role that was task specific. For example, the primary caregiver and a younger sister for one of the networks separated their caregiving tasks, while the youngest sister in the family served as the supervisor by providing suggestions for care. The statements below reflect their task-oriented model of care.

I provide caregiving while my younger sister cleans the room and washes the clothes.
(Primary caregiver for network #14)

Sometimes I remind her about the medications she has to give. Mostly, I just recommend. I will remind her and ask her if she did this or that. (Youngest sister of network #14)

The care sharing pattern tended to involve both large (8 to 10 individuals) and small (4 to 5 individuals) caregiving networks that consisted of both intergenerational family members and community members. Prior research has noted that small family network structures tend to provide more support to elderly family members in need than do large family structures.^{28,29}

The community network members, involved in the care sharing pattern, were found to have resided in the residential area of the stroke victim for either a long or short period of time. This is interesting, given that community members who provide caregiving generally tend to reside in the residential area of the care receiver for an extended period of time, rather than for a short period of time.¹⁴

The networks that used the care sharing pattern tended to express a willingness to engage in caregiving activities based upon of their internal motivation to do so. This was not surprising, given prior research has noted similar motivation behaviors related to family caregivers of individuals requiring long-term care.³⁰ In addition, the fact that all members of the networks were religious (i.e. primarily Buddhist) would have had an influence on their willingness to engage in caregiving.³¹ According to Buddhism, it is of great merit to give and expect nothing in return (*metta or good will*).³²

The care sharing networks focused on exchanging, with each other, the activities of caregiving, as well as sharing finances, time commitments and caring information. Five caregiving networks (#s: 2, 4, 8, 17 & 18) worked on balancing their schedules, while three (#s: 7, 11 & 14) provided care only when they had available time. When care was provided only when a network member was available, there tended to be less sharing of care responsibilities. This appeared to occur due to of a separation of roles, with little or no assistance given to other members of the caregiving network.

Balancing schedules or providing care based upon available time was reflected by such statements as:

If he (my third son) was not asleep, he would come to see his father at 1 a.m. or 2 a.m. He and my daughter would share the caregiving. One of them would make the blenderized diet, while the other would carry out another task. They balanced their schedules with each other. (Primary caregiver of network # 18)

As soon as I arrive home, she (a non-primary caregiver) stopped doing everything. I inherited all of the caregiving tasks once I got home. If I was late getting home, there were problems because she (non-primary caregiver) simply stopped working at 5 p.m. (Primary caregiver of network # 7)

Four caregiving networks (#s: 4, 14, 17 & 18) had consistent financial support, while four received only occasional support (#s: 2, 7, 8 & 11). The networks that had consistent financial support were found to engage, on a regular basis, in sharing the caregiving compared to those who had only occasional financial support. Most likely this was due to the fact that networks with financial support were more able to pay for services or amenities that could assist the network with caregiving.

The members of five caregiving networks (#s: 4, 7, 11, 17 & 18) tended to engage most often in direct communication, while three (#s: 2, 8 & 14) communicated most often in an indirect manner. Networks that utilized direct communication were more likely to consistently engage in sharing care compared to networks that used indirect communication. No doubt, direct communication facilitated the flow of caregiving information, which, in turn, fostered the effective use of the care sharing pattern.

Regarding close relationships, four caregiving networks (#s: 4, 11, 17 & 18) demonstrated close relationships, while four (#s: 2, 7, 8 & 14) had

relationships that involved conflict. The fact that there was conflict within the relationships, in some networks, was not surprising given that is has been noted siblings, in particular, often engage in conflict when providing care to an elderly parent.⁶ Regardless of the type of relationships that existed within the networks, all eight carried out, to some degree, care sharing, which is very similar to the constellation pattern of caregiving shared among biological and fictive kin,³³ and the reinforcement teamwork model of stroke caregiving.⁹ In addition, the fact there was diversity among the various members of the sharing networks allowed for a greater variety of available caregiving skills.³³

The adequacy of sharing the caregiving was found to be affected by each network member's willingness to exchange and/or share the factors of time commitment, finances, communication and relationships. Six of the eight networks (#s: 2, 4, 8, 11, 17 & 18) that engaged in sharing the caregiving, found their caregiving to be adequate (i.e. fulfilled the caregiving needs of the stroke victim), while only two (#s: 7 & 14) described their caregiving as inadequate.

Dual care refers to the pattern of social exchange behavior that involves two primary caregivers who care for the stroke victim using a "buddy system." In other words, the caregiving becomes a shared experience which is much different from the caregiving provided by dual-earner couples to their elderly parents.³⁴ Dual care, however, is similar to complementary care where the actions of one member of the group fit together with the action of another member of a group.³⁵

Four networks (#s: 5, 6, 12 & 16) were found to use the pattern of dual care. Dual care or the buddy system involved the two primary caregivers not dividing the caregiving activities, but rather doing them together. However, if one caregiver had limitations with a specific caregiving task, the other caregiver

was found to totally take on that task. An example of dual care was reflected in the following statement by one of two primary caregivers administering care to a bedridden stroke victim:

He (the first primary caregiver) helped me (the second primary caregiver) with everything. I could not do care without him because our family member is very heavy. He would spasm when we lifted him. Both of us needed to do the care. I could not lift him by myself. (One of two primary caregivers for network #5)

The dual care pattern involved two medium sized (6 to 7) and two small sized (4 to 5) networks that consisted of intergenerational family and community members. Three of the networks provided caregiving by way of a set time schedule, while one had to use ongoing negotiation for establishing who would be able to provide care and when that care could be provided. As demonstrated by the following comments, community members involved in providing dual care generally had resided in the stroke victim's residential area for a respectable period of time.

We (stroke victim and wife) have known our neighbors for six years. When I (wife) have to lift my husband (stroke victim), I call on the neighbors to receive help. (One of two primary caregivers of network # 16)

Of these four dual care networks, two carried out the task of caregiving with willingness, while two did caregiving out of endurance. Thus, dual care networks utilized a combination of internal and external motivation in order to complete their caregiving responsibilities. This finding is noteworthy when viewed within the context of the beliefs of the philosopher, Boszormenyi-Nagy, who said people provide care to each other out of loyalty based upon blood relationships,³⁰ and the findings of Carruth,³⁶ who suggested that ongoing intergenerational exchange was motivated by obligation and family loyalty.

All four networks had consistent financial support, as reflected by the following statement from one network member:

My eldest sister and eldest brother come to visit every month and give me money. Thus, I can pay for the cost of the ambulance service to the hospital. (One of two primary caregivers of network #6)

As reflected in this statement, like the networks engaged in sharing care, the dual care networks also were able to pay for needed services in providing stroke caregiving.

Although all four dual care networks were found to use direct communication when dealing with caregiving issues, only two demonstrated the presence of close network member relationships. Unfortunately, the other two networks demonstrated relationships wrought with conflict. An example of the close relationship that existed within one of the dual networks is listed below:

Sometimes, I wonder why I take care of him (father-in-law)). I did not take care of my own father before he passed away. However, I was willing (tem-jai) to care for my father-in-law because my husband is so nice. He provides me with many things that I want. My father-in-law has always been so nice by sweet-talking to me all the time. He is a good man. (One of two primary caregivers of network # 5)

All four caregiving networks perceived their caregiving to be adequate, even though in one network (#6) one of the two primary caregivers was not able to fulfill all of the caregiving tasks required.

Supplementary care refers to the pattern of social exchange behavior in which the primary caregiver is ultimately responsible for providing care, while non-primary caregivers provide care only when available. As a result, the caregiving becomes varied

and not always consistent. Six networks (#s: 1, 3, 9, 10, 13 &15) were found to use this pattern of care. Although the primary caregivers, in supplementary care networks, obtained occasional assistance from other members of the caregiving network, they still remained solely responsible for delivery of the caregiving tasks. An example of a supplementary care network is reflected in the following statements made by the wife of a stroke victim:

I was not skillful but I needed to be skilled. The nurse taught me..... My daughter didn't do it...I had to go and learn because I had no one. I needed to learn so that I could do the care. (Primary caregiver of network #9)

The supplementary networks consisted of a variety of sizes. Three of the networks were small (4 to 5 individuals), two were medium (6 to 7 individuals), and one was large (8 to 10 individuals). These networks were composed primarily of spouses of the stroke victims (wives in four of the six networks), with supplemental assistance coming from intergenerational family and community members who provided care when they were available or when they wanted to offer care. The limited availability of non-primary caregivers was reflected by the following statements:

Everyone will provide help at the time they are available. Sometimes my mother and father expect their children to take care of them. In order for me to sleep in late on the weekend, I have to argue with my parents. I do not want to wake up on the weekends at the same time I do during the week when I have to go to work. My mother has her own timetable. She thinks that I should wake up early to help her on the weekends. (Daughter from network # 10)

The previous statement is interesting when one considers, within the Thai culture, if a spouse

caregiver is unable to provide care the adult children are considered next-in-line to take on the task of proving care for their elderly parents.³⁷ Not surprisingly, the community members, who were part of the supplementary care network, tended to have resided in the same residential area as the stroke victim for an extended period of time.

Four of the supplementary networks provided care willingly, while two did it with a sense of endurance. Their endurance appeared to be the result of external motivation brought on by the family's decisions related to caregiving. Their sense of endurance is reflected in the following statements made by a disabled network member who was compelled by her family to be the primary caregiver:

Yes. It is my obligation to do caregiving. Each person in our family has his/her own responsibilities. My sister is the leader of our family and takes on the role of making our income. If nobody makes an income we all would starve. (Primary caregiver of network #10)

The financial support of the supplementary care networks varied between consistent and occasional. Four of the networks had consistent (monthly) financial support, while two had only occasional financial support. The fact that some of the networks had occasional financial support posed additional problems because the networks did not always have the resources needed to obtain assistance or materials for caregiving. This was especially true for the small networks.

Three of the supplementary networks primarily used direct communication, while three primarily used indirect communication. In the networks that tended to use indirect communication, the caregiving exchange between the primary caregiver and other members of the caregiving network were negatively influenced. This most likely contributed to the fact that five of the six supplementary care networks had relationships involving conflict. Only one of the six

networks demonstrated close relationships among the network members. An example of a relationship involving conflict (the eldest daughter did not want to provide care, but had to because no one else was available) is demonstrated in the following statements:

I must take care of my mom because there is no one else to care for her. One family member said she had no time. Another one said she had to work. My younger sister is capable of giving care, but she cannot stay with her. OK! No problem! Yes, I can do this. She is my mom. (Primary caregiver of network # 1)

Although the supplementary care networks tended to be primarily small in size, involve a primary caregiver who was a spouse and have members who were not always freely available, it was surprising to find that four of the six still found their caregiving to be adequate.

In summary, the three patterns of social exchange behaviors (sharing care, dual care and supplementary care) found in this study provide additional understanding of the actions of the primary and non-primary members of a stroke caregiving network. These patterns were found to be influenced by the: structural factor of size; informational factor of communication; social factors of time and duration; economic factor of finances; and, psychological factors of relationships and satisfaction.

Limitations and Recommendations

Like all studies, this study has limitations. Due to the study design, it was not possible for the primary investigator to observe caregiving exchange activities all of the time. Thus, validation of the consistency of exchange behaviors of the members of the caregiving networks could not be made. In addition, the study participants were from one geographical area of Thailand (i.e. Bangkok). Therefore, generalizability of the findings to other geographic areas of Thailand

may not be possible. Finally, since the raw data required translation from Thai into English, it is possible some of the contextual meaning of the findings were altered.

Future studies need to consider examination of social exchange behaviors of stroke caregiving networks located in other geographical areas of Thailand. Due to the stressors placed upon primary stroke caregivers, it would be advisable to examine the impact caregiving has upon them, how they contend with the daily demands of caregiving and what community resources are needed to assist them with their caregiving activities.

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เครือข่ายผู้ดูแลผู้ป่วยอัมพาตจากหลอดเลือดสมองในกรุงเทพฯ: รูปแบบการช่วยเหลือทางสังคม

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บทคัดย่อ: การศึกษาครั้งนี้มีวัตถุประสงค์เพื่ออธิบายรูปแบบการช่วยเหลือทางสังคมของเครือข่ายผู้ดูแลผู้ป่วยอัมพาตจากหลอดเลือดสมองในกรุงเทพฯ แนวคิดเครือข่ายทางสังคมนำมาซึ่งในการศึกษาการเครือข่ายความสัมพันธ์ระหว่างกัน และทฤษฎีการแลกเปลี่ยนทางสังคมนำมาซึ่งในการศึกษาการแลกเปลี่ยนความช่วยเหลือในเครือข่ายผู้ดูแลผู้ป่วยอัมพาตจากหลอดเลือดสมองจำนวน 18 เครือข่าย ผู้ป่วยอัมพาตสูงอายุในกรุงเทพมหานคร ผู้ให้ข้อมูลจำนวน 42 คน คือผู้ดูแลหลักจำนวน 22 คน และสามชิกเครือข่ายจำนวน 20 คน การศึกษาครั้งนี้เป็นการวิจัยเชิงชาติพันธุ์วรรณ (Ethnographic study) เก็บข้อมูลโดยการสังเกต การสัมภาษณ์แบบเจาะลึกและการพูดคุย การบันทึกและวิเคราะห์เครือข่ายระหว่างเดือนกรกฎาคมถึงเดือนกันยายน 2551 การวิเคราะห์บุริบทของข้อมูลตามขั้นตอนของ Leocompete และ Schensul โดยใช้ Nvivo software program.

ผลการศึกษาพบรูปแบบการช่วยเหลือทางสังคมในเครือข่ายผู้ดูแลผู้ป่วยอัมพาตจากหลอดเลือดสมองในบริบทกรุงเทพฯ เป็น 3 รูปแบบคือ การแบ่งกันดูแล (Sharing care) การร่วมกันดูแล (Dual care) และการสนับสนุนการดูแล (Supplementary care) ปัจจัยที่เกี่ยวข้องประกอบด้วยการลืมสาร ขนาดเครือข่ายระยะเวลา เวลาที่ให้ในการดูแล การเงิน สัมพันธภาพและความพึงพอใจ

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