Caregiver Role Strain and Rewards: Caring for Thais with a Traumatic Brain Injury

Niphawan Samartkit, Saipin Kasemkitvattana, Orapan Thosingha, Thavatchai Vorapongsathorn,

Abstract: Using a predictive model, this study sought to examine, among 291 traumatic brain injury (TBI) survivor-caregiver pairs, causal relationships among care receiver functional status, relationship of caregiver with care receiver, caregiver mutuality, caregiver preparedness, care receiver amount of care and caregiver health as they relate to caregiver role strain and rewards of caregiving. The conceptual framework was guided by the symbolic interactionist perspective of role strain theory and related literature regarding caregiving and TBI survivors. Data were collected, in eight provinces in eastern Thailand, via nine questionnaires, and analyzed through descriptive statistics, Pearson's correlation coefficient and path analysis.

The final model fit the data well and explained variance in caregiver strain (46%), rewards of caregiving (41%), caregiver health (19%) and amount of care (33%). The model illustrated care receiver function had a direct negative effect on amount of care. Care receiver amount of care had a direct positive effect on caregiver role strain, a negative direct effect on caregiver health and mediated the effect of care receiver function on caregiver role strain and health. The caregiver/care receiver relationship had a positive direct effect on the caregiver's health, while the caregiver's health had a positive direct effect on the caregiver's role strain. The caregiver is health mediated the effect of the caregiver/care receiver relationship on the caregiver's role strain. Caregiver mutuality had a direct positive effect on amount of care and rewards of caregiving, but a negative direct effect on caregiver mutuality on caregiver health. Caregiver preparedness had a direct positive effect on rewards of caregiving and caregiver health, and a direct negative effect on caregiver strain. The findings suggest that enhancing caregivers' perceptions of the rewards of caregiving.

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Introduction

In Thailand, traumatic brain injury (TBI) is a common, costly and debilitating health problem among young people. Although advances in medical and nursing practice can enhance survival of TBI victims, those who have moderate to severe injuries experience life-long disabilities, including varying degrees of dependence, which require ongoing care

Correspondence to: Niphawan Samartkit, RN, PhD (Candidate) Faculty of Nursing, Mahidol University, Bangkok, Thailand. E-mail: Niphawan@buu.ac.th Saipin Kasemkitvattana, RN, DNS. Associate Professor, Faculty of Nursing Mahidol University, Bangkok, Thailand. Orapan Thosingha, RN, DNS. Assistant Professor, Faculty of Nursing Mahidol University, Bangkok, Thailand. Thavatchai Vorapongsathorn, PhD. Associate Professor, Faculty of Public Health Mahidol University, Bangkok, Thailand. from family members and health care providers.^{1, 2} Thus, it is not surprising that one's family, as well as his/her family environment, have been found to play an important role in long-term outcomes for TBI survivors.^{1, 2}

Traditionally, within the Thai culture, one's family, especially the family caregiver, has been the main support system and the one who provides care for family members who experience a TBI.³ This is significant in that newly diagnosed TBI survivors often focus on the familiar, i.e. a family member, to achieve orientation.^{3, 4} Therefore, family caregiving has been recognized as a critical determinant of successful outcomes and one of the most important social issues for the TBI survivor.¹⁻⁴

Compared with other illnesses, the cognitive and physical impairments that occur, secondary to a TBI, create long-term effects not only on the victim of the injury, but also on his/her family. Prior research has found that family caregivers of TBI survivors frequently experience caregiving difficulties and high levels of burden/ stress, during acute hospitalization and the long-term recuperation period of their injured family members.¹⁻⁷

Empirical studies have shown caregivers have simultaneous negative and positive perceptions to caregiving, with more positive perceptions linked to fewer negative outcomes.⁸⁻¹⁴ Caregivers who have a positive perception of their abilities to implement caregiving successfully have been found to: spend more time giving care; have a more positive attitude regarding their role; and, report greater ability to minimize the stress of challenging caregiving events.^{8 -12} It would seem likely, therefore, that positive appraisal of and responses to caregiving might serve a similar protective role among family caregivers of survivors of a TBI. However, research is needed to identify specific factors that predispose caregivers to more positive perceptions of their abilities to appropriately

perform their caregiving role and protect them from negative consequences of caregiving. Therefore, this study sought to examine, among TBI survivorcaregiver pairs, causal relationships among care receiver functional status, caregiver relationship with care receiver, caregiver mutuality, caregiver preparedness, care receiver amount of care and caregiver health, as they relate to caregiver role strain and rewards of caregiving.

Conceptual Framework and Related Literature

The conceptual framework was guided by the symbolic interactionist perspective of role strain theory,¹⁵ as further developed by Archbold and colleagues,^{9, 10} and related literature regarding caregiving and TBI survivors. Symbolic interactionism is based on the belief that human beings act toward things on the basis of the meanings the things have for them.¹⁶

Archbold and colleagues ^{9, 10, 13} characterized caregiving as a role and viewed caregiving in the family through the symbolic interactionist perspective of role strain theory, which links the perspective of the caregiver to what is occurring in the caregiving situation. According to this perspective, families are social groups and consist of individuals who develop, through social interaction with other family members, a concept of self and an identity. Such interaction enables them to independently assess and assign value to their family activities.

Caregiver role acquisition involves the concepts of self and identity, and the meaning of the situation and role taking. In order to shape a role, one: a) takes into account important aspects of one's self; b) appraises the situation and comes to understand its meaning for him/her; and, c) imagines him/herself in the caregiving role.¹⁶ All

experiences that arise from an interaction shape subsequent interactions. Thus, the way family caregivers learn the role of caregiver may occur reflexively through one's thoughts, dialogue with self or interactions with others. Meaning of family caregiving arises out of social interactions the caregiver has with the care recipient, as well as from interactions between the caregiving dyad and others. Hence, within each unique caregiving situation, the meaning it has to the caregiver may influence his/ her behavior.

The caregiving phenomenon is complex and affected by numerous individual, family, environmental and service variables. For some caregivers and their families providing care can be difficult and burdensome, placing family members and care receiver at risk for health problems.^{17, 18} However, in addition to the quality of the caregivercare receiver relationship and the nature of the caregiving activities, the ability and willingness of family members to provide care determine whether caregiving is satisfying and contributes positively to family members and the family system.9-11 Examining the framework of caregiving-at-home can: a) assist in understanding how the caregiver learns the role and evaluates his/her ability to perform the caregiver role, including both positive and negative experiences of caregiving; and, b) help in understanding variables that mediate the effects of the onset and nature of caregiving.9 In a general sense, this framework posits antecedents of caregiving that influence the nature of the caregiving role, which, in turn, influence the response to family care and ,subsequently, influence the outcome of caregiving for the caregiver, care receiver, family and health care system.^{9, 13}

Although family caregivers may desire to provide care for family members with a TBI, it is challenging for caregivers to care simultaneously for a TBI survivor and one's self. Family members are confronted, as they enter the role of caregiving, with a set of immediate problems that can create role strain, as well as difficulties associated with performing the role of caregiver.^{1, 8-13} The demands of caregiving can change the caregivers' abilities, daily routines, marital relationships, money management and social activities. These changes often lead to increased role strain within families that, in turn, influence the caregivers' ability and willingness to provide necessary care to their ill family members. Given that TBIs usually occur among youth, it is not unusual for their caregivers to be parents or a spouse who have multiple role obligations within the family.⁴⁻⁶

Although, when the demands of social roles conflict with caregiving duties, caregivers may experience role strain,¹⁹ caregivers report few symptoms of distress and indicate receiving positive gains from their experiences.^{8, 14, 18} The rewards of caregiving have been described as positive feelings and a sense of pride, generated during the caregiving process, that contribute to a caregiver's reduction in negative feelings regarding the obligations, burdens and stresses of caregiving. ^{13, 20} Prior research suggests that rewards are a vital component of caregiving and a fundamental means of encouraging caregivers to perform their best in the caregiving role.^{11-14, 21-23} In addition, the rewards of caregiving have been found to be negatively related to caregiver role strain. 21-23

As one would suspect, the greater the impairment of the care receiver the greater the amount of care required.^{13, 24} Thus, higher levels of disability and direct care are associated with higher levels of caregiver role strain²⁴⁻²⁸ and lower levels of caregiver health status.^{17, 18, 27, 29-31} In turn, when a caregiver's health status is poor, he/she is known to be more likely to suffer role strain, ^{17, 29-31} thereby creating a cycle of poor health and role strain.

However, inconsistent findings exists

regarding whether poor care receiver functional status is associated with higher levels of caregiver burden^{7, 24} and the experience of caregiving rewards.^{7, 23} However, it is known that as caregivers provide more care, care receivers depend more on their assistance, which, in turn, encourages caregivers to feel they are playing an important role.^{24, 32}

Higher levels of mutuality^{9-11, 22, 33} and preparedness for the role of caregiver also have been shown to be associated with lower levels of caregiver role strain,^{9-11, 28, 32, 34, 35} which, subsequently, encourages a caregiver to perceive his/her role of caregiver as more rewarding.^{12, 13, 21-24} Because mutuality enables a caregiver to continue caregiving, despite difficult situations, familiarity between a caregiver and care receiver fosters caregiver performance in the caregiving situation. However, spouses are known to suffer more psychological distress and be at greater risk of experiencing burden when providing care than are parents or adult children.^{1, 4, 24, 27, 29}

In this study, caregiving was viewed from a dyadic interaction perspective with both negative and positive responses to caregiving and role strain being evaluated from the caregivers' perspectives in regards to the caregivers' relationship with care receivers, mutuality, preparedness and health, and the caregivers' functional status and amount of care (See Figure 1). The following hypotheses were posed:

Care receiver functional status would have:

 a) negative direct effect on care receiver amount of care and caregiver role strain;
 b) positive indirect effect on caregiver role strain, mediated through care receiver amount of care;
 c) positive direct effect on caregiver health; and, d) negative indirect effect on caregiver health, mediated through care receiver amount of care;



Figure 1 Hypothesized Model for the Study

CR = Care Receiver CG = Caregiver

- Care receiver functional status would have a negative direct effect on caregiver rewards of caregiving.
- 3) Relationship of caregiver with care receiver would have: a) either a negative or positive direct effect, depending upon the type of relationship, on caregiver role strain; b) a positive direct effect on caregiver health; and, c) a negative indirect effect on caregiver role strain, mediated through caregiver health.
- 4) Caregiver mutuality would have a: a) direct positive effect on care receiver amount of care; b) negative direct effect on caregiver role strain; and, c) positive direct effect on caregiver rewards of caregiving.
- 5) Caregiver preparedness would have a direct negative effect on caregiver role strain and a direct positive effect on caregiver rewards of caregiving.
- Caregiver rewards of caregiving would have a direct negative effect on caregiver role strain.

Method

Design: A descriptive, correlational, cross-sectional design was used.

Ethical Considerations: The study was approved by the Institutional Review Board of Mahidol University, and the Directors of the eight provincial community health care centers and hospitals used as data gathering sites. Potential subjects, who met the inclusion criteria, were approached and informed about: the purpose of the study; what was involved in being part of the study; having their confidentiality and anonymity would be maintained; and, being able to withdraw at any time without negative repercussions. Those who expressed a willingness to participate were asked to sign a consent form.

Sample: The sample consisted of 291 family caregiver/care receiver dyads who resided in eight provinces (Chon Buri [n = 148]; Chachoengsao [n = 12; Rayong [n = 23]; Chantaburi [n = 16]; Prachinburi [n = 21]; Srakaew [n = 40]; Nakorn-Nayok [n = 20]; and, Trat [n = 11]) in eastern Thailand. These provinces were selected because they have some of the highest incidence, in the country, of traffic accidents resulting in death and injury, especially TBI. After approval to conduct the study was obtained, nurses working in the 8 provincial community health centers and 4 outpatient neurological clinics were approached and asked to provide the primary researcher (PI) with names, addresses and telephones numbers of potential family caregiver/ TBI survivor dyads, with whom they were associated and felt met the inclusion criteria. Of the 314 family caregiver/care receiver dyads approached 291 consented to participate in the study. Most of the subjects (n =243; 83.4%) were located via one of the 8 health care centers, although 48 (16.6%) were located via the 4 clinics.

Inclusion criteria for family caregivers (parents, adult children, spouses or relatives) were those who: a) identified themselves as the major providers of direct care for their ill family member; b) were at least 18 years of age; c) had provided unpaid care for at least one month; d) had good cognitive ability; and e) were willing and able to respond to the items in the study's questionnaires. The inclusion criteria for care receivers were those who were: a) at least 15 years of age; b) diagnosed as having experienced a TBI; c) discharged from the hospital after injury and living with their family for at least one month; d) disabled and required rehabilitation; and, e) scored a level 2 to 7 on the Extended Glasgow Outcome Scale (GOS-E).³⁶ The reason for the care receiver inclusion criteria of GOS-E score of a level 2 to 7 was because those who score at level 1 have a high mortality rate and

are not likely to be treated on an outpatient basis, while those who score at level 8 are likely to have a good recovery and not require a caregiver.

The family caregivers primarily were a: female (n = 256; 88%) with an average age of 46.55 years (range = 18 - 80 years); parent (n = 126; 43.3%) or spouse (n = 89; 30.6%);Buddhist (n = 278; 95.5%); married (n = 222; 76.3%); primary school graduate (n = 200; 68.7%); employed part-time in a job that provided flexible working hours (n = 175; 60%), but an insufficient income (n = 164; 56.4%); and, involved in caregiving for approximately 13 months (range =1 - 264 months). Among the caregivers: 80.1% (n = 233) had no prior experience providing care; 82.8% (n = 241) had not received caregiving training; 28.5% (n = 83) spent one to five hours per day providing care, while 21.6% (n = 63) spent more than 21 hours because of the severe disability or vegetative state of the care receiver; 66.3% (n = 193) had assistance from a secondary caregiver; 58.8% (n = 171) provided care for other family members in addition to the TBI survivor and ; and, 76.3% (n = 222) provided care out of responsibility and love.

The TBI care receivers primarily were: males (n = 242: 83.2%); 37.02 years of age (range = 15 - 87 years); Buddhist (n = 283: 97.3%); single (n = 123; 42.3%); educated at the primary school level (n = 141; 48.5%); incapable of working to support themselves (n = 245; 84.2%); living in their own homes (n = 114; 38.2%); injured due motorcycle accidents (n = 238; 81.8%); diagnosed with cerebral contusions (n = 131; 45%) and subdural hematomas (n = 109; 37.5%); classified as sustaining severe TBIs (n = 267; 91.8%); post-neurosurgical patients (n = 159; 54.6%); and, ranked, on average, at the 4.45 level (severe disability) on the GOS-E.³⁶

Instruments: A total of nine instruments were used in the study. These included the:

a) Extended Glasgow Outcome Scale (GOS-E)³⁶ b) Care Receiver and Caregiver Characteristics Ouestionnaire (CRCCO) [developed, in Thai, by PI]; c) Preparedness for Caregiving Scale (PCS); 9, 20 d) Caregiver Mutuality Scale (CMS); 9, 20 e) modified version of the Amount of Care Activities Scale (ACAS-mv);²⁰ f) Caregiver Role Strain Scale (CRSS);²⁰ g) modified version of the Rewards of Caregiving Scale (RCS-mv);³⁷.; h) modified version of the Functional Status Scale (FSS-mv);³⁸ and, i) SF-36.³⁹ Permission was obtained to use all copyrighted instruments. The Thai translated and back-translated versions³⁷ of six of the instruments (PCS, CMS, CRSS, ACAS-mv, RCS-mv, and SF-36³⁹) were used, while two of the instruments $(GOS-E^{36} \text{ and } FSS-mv^{38})$, originally written in English, required translation into Thai and back translation into English, until no changes in the meaning of the respective items occurred. All instruments were pilot tested, prior to use in the study, on 30 caregivers of TBI survivors whose characteristics were similar to those of the study sample. The instruments' reliabilities, in the pilot study, ranged from 0.85 to 0.95.

The Extended Glasgow Outcome Scale (GOS-E),³⁶ a hierarchical 1-item instrument, was used for the purpose of assessing the disability level of TBI care receivers. Examples of areas assessed included the care receivers' ability to: communicate, follow commands, self-groom and self-feed, engage in recreational and social activities, and be employed. To determine care receivers' levels of dependence, the PI conducted a physical examination on care receivers and asked the caregivers about the care receivers' ability to engage in certain activities. Questions asked of caregivers included: a) "What would your family member, with a TBI, do if a glass was dropped and broken?" and, b) "Could your family member, with a TBI, make a telephone call to report any problems he/she was having?" Based upon the results of the care

receivers' physical examinations, and the responses provided by caregivers, the PI determined the caregivers' levels of dependence as described in the instrument. Levels of dependence range from 1(has a high chance of mortality, presence of a 3 or 4 on the coma scale) to 8 (has a very good chance of recovery, is very likely to live a normal life, able to care for self and able to go back to work). A low score indicated severe disability, while a high score indicated no or minimal disability. The majority of care receivers, in the study, ranked in the middle of the scale at slightly above a level 4 (high degree of impairment, needs constant care in performing a number of daily live activities).

The researcher developed Care Receiver and Caregiver Characteristics Questionnaire (CRCCQ) was used to obtain demographic information about each care receiver and caregiver. Information obtained about the care receiver included: gender, age, religion, marital status, educational level, work status, living accommodations, type of accident causing the TBI, type of brain injury, surgical procedures done as result of TBI, and level of mental disability. Caregiver information included: gender, age, relationship to care receiver, religion, marital status, educational level, work status, sufficiency of income level, length of caregiving experience, previous caregiving experience, training as a caregiver, hours spent per day giving care, presence of a secondary caregiver, caregiving responsibilities to other family besides the TBI survivor, and reasons for providing care to the TBI survivor.

The Preparedness for Care giving Scale (PCS)⁹ was used to measure how well prepared the caregiver believed he/she was for the tasks and stress of assuming the caregiver role for his/her family member with a TBI. The scale consisted of 8 items, which asked how well prepared the caregiver was to provide care to meet the physical and emotional needs of the family member with a TBI.

Each item was scored on a 5 point scale, where 0 = "not at all prepared" to 4 = "very well prepared." A total score was computed by summing the responses across all items. High scores reflected a high level of preparedness, while low scores reflected a low level of preparedness. In this study, the internal consistency reliability of the PCS was 0.88.

The Caregiver Mutuality Scale (CMS)⁹ was used to assess the quality of the caregiver/care receiver relationship. The scale consisted of 15 items, such as: a) "To what extent do you and your family member with a TBI see eve to eve?" b) "How close do you feel to your family member with a TBI?" and, c) "How much does your family member with a TBI express feelings of appreciation for you and the things you do?" Each item was scored on a 5 point scale, where 0 = "not at all" to 4 = "a great deal." A total score was computed by summing responses across items and then calculating an average score. High scores reflected the presence of a high level of mutuality (i.e. love, shared pleasurable activities and values, and reciprocity), while low scores suggested a low level of mutuality between caregiver and care receiver. In this study, the reliability for the CMS was 0.90.

A modified version of the Amount of Care Activities Scale (ACAS-mv)²⁰ was used to determine the number and type of care activities the caregiver perceived he/she provided for the care receiver. The PI modified scale consisted of 90 items regarding TBI-related caregiving activities. The type of care provided focuses on: a) personal care; b) mobility and protection; c) illness-related care; d) transportation, cooking, and housekeeping; e) little extras and emotional support; f) dealing with symptoms of dementia and difficult behavior; and, 7) arranged care. Examples of items included: a) "Do you do shopping and run errands for your family member with a TBI?" b) "Do you have to assist your family member with a TBI regarding walking around the house?" "If so, do you have to give him/her your arm or get him/her a walker?" and, c) "Do you have to keep an eye on your family member with a TBI to make sure he or she is safe?" Face validity of the ACAS-mv was evaluated by 4 caregivers who indicated they understood the meaning of each item, confirmed they had experience in providing all 90 caregiving activities and agreed that all 90 items were appropriate. Content validity of 0.98 for the ACAS-mv was determined by 5 clinical nurses who had 12 years of experience working with TBI survivors and their families. All items requested a dichotomous response, where "1 = yes" and "0 = no." A total score was calculated by summing responses across all items. High scores reflected the presence of a high number of caregiving activities, while low scores reflected a low number of caregiving activities. The scale's reliability, in this study, was 0.94.

The Caregiver Role Strain Scale (CRCS)^{9, 20} which consisted of two parts, was used to measure: 1) caregivers' perceptions of difficulties encountered in completing each caregiving activity assessed in the ACAS-mv (90 items); and, 2) amount of emotional strain caregivers perceived in contending with situations related to the caregiving role (43 items). In Part I of the scale, caregivers were asked to indicate, if they carried out a specific caregiving activity and the level of difficulty encountered in completing it. Responses were rated on a 5-point scale where 0 = "easy" to 4 = "very" hard." In Part II of the instrument, caregivers were asked to assess the level of emotional strain in contending with caregiving obligations related to: a) communication problems with care receivers (7 items); b) worries about care receivers, self, future and family (15 items); c) a lack of resources (5 items); d) the levels of tension in the caregiver/care receiver relationships, as a result of caregiving activities (4 items); e) the caregivers' feelings of being manipulated or taken advantage of by care

receivers (4 items); f) economic burdens (4 items); and, g) the different caregiving experiences of caregivers (4 items). Questions included in the CRCS addressed such things as how much the caregivers worried about the health of their family members with a TBI, as well as the finances available for care and the ability to do things for their respective care receivers. Responses for Part II were rated on a 5-point scale, where 0 = "not at all" to 4 = "a great deal. A total score was obtained by summing across all items, in Part I and Part II, and then calculating an average score. High scores indicated high caregiver strain from carrying out caregiving activities, while low scores indicated a lack of or low level of caregiver strain. In this study, reliability for the scale was 0.96.

A modified version of the Rewards of Caregiving Scale (RCS-mv) ³⁷ was used to measure caregivers' positive feelings developed during the caregiving experience. The scale consisted of 15 items that were responded to on a 4-point scale, where 0 = "not at all" to 4 = "a great deal." Examples of items included: a) "To what extent does caring for your family member with a TBI help you feel like you are doing something important?" and, b) "Does caring for your family member with a TBI help you feel good about yourself?" The overall score was computed by summing across all items and calculating an average score. High scores reflected a perception of high rewards from caregiving, while low scores suggested little or no reward from the caregiving experience. For this study, reliability of the scale was 0.93.

A modified version of the 18-item Functional Status Scale (FSS-mv) ³⁸ was used to assess the functional level of care receivers. The scale was divided into five subscales: (a) memory (3 items); (b) organization/productivity (3 items); (c) inappropriate behavior (1 item); (d) mobility/ independence (5 items); and, (5) physical limitations (6 items). Examples of memory and inappropriate behavior items included: a) "Has a lot of trouble keeping track of where things are around the house." and, b) "Says the wrong thing a lot." The items for memory, organization/productivity and inappropriate behavior, originally scored on a 4-point scale, were modified by the PI to a 5-point scale scoring, in order to indicate the presence of an unconscious/vegetative state. Thus, scores ranged from 0 = "vegetative state" to 4 = "never." Items addressing mobility/independence (i.e. "How much problem does the family member with a TBI have going shopping?") and physical limitations (i.e. "With respect to walking, how well does the family member with a TBI do?") were scored on a 4-point scale, where 1 = ``can't do/have a problem with thisactivity" to 4 = "no problem." The total score for the scale was obtained by summing across all items and then calculating an average score. High scores reflected a high level of care receivers' functional status. For this study, reliability of the scale was 0.92.

The SF-36³⁹ was used to assess caregivers' health status. The 36-item questionnaire assessed eight health concepts: physical functioning, rolephysical, role-emotional, bodily pain, general health, mental health, social function and vitality. Examples of items were: a)" Compared to one year ago, how would you rate your health in general now?" b) "During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors or groups?" and, c) "How much bodily pain have you had during the past 4 weeks?" Possible responses varied depending upon the item. Examples of possible responses included: a) 1 = "always" to 5 = "never"; b) 1 = "excellent health" to 6 = "poor health"; c) 1 = much better than a year ago" to 5 ="much worse than a year ago"; and, d) 1 ="definitely true" to 5 ="definitely false." Ten items

required recoding so higher scores reflected a better level of health. To obtain a total score, numerical values for all items were summed and then converted into raw scores, according to the instrument's designated conversion scale. High scores indicated a high status of health, while low scores suggested low health status.

Procedure: Potential caregivers were either telephoned at their homes or contacted in person while at the hospitals' neurological out-patient clinics with their respective care receivers. Once the caregivers, who met the inclusion criteria, consented to participate in the study, a time was arranged with the caregivers for the PI or one of her trained research assistants to administer the study questionnaires. Caregivers then were asked where they preferred to have the questionnaire administration conducted (at home, in the hospital clinic or via mail). The majority (n = 251; 86.3%)preferred to complete the questionnaires at home so as to have privacy and feel they had additional time to think about their responses. Twenty-three (10.9%) of the 251 subjects completed the questionnaires via mail once the PI confirmed (in person or by telephone) they understood the: a) questionnaire instructions; b) instructions only to complete the questionnaires; and, c) PI was available, by telephone, should they have questions. Upon return of the completed mailed questionnaires, if item responses were missing or confusing, the PI contacted the caregivers, by telephone, to clarify or obtain missing information. The remaining 40 (13.7%) of the 251 caregivers preferred to have the questionnaires administered in a private area, while at the neurological out-patient clinic for a follow-up visit with their care receivers, or, if they lived a considerable distance from the clinic, to have the questionnaires mailed to them.

So care receivers' levels of disability could be assessed, as well as to assure they met the inclusion criteria, the first questionnaire administered was the GOS-E.³⁶ Care receiver whose caregivers preferred to complete mailed questionnaires and return them in one week, via a provided self-addressed stamped envelope, were administered the GOS-E,³⁶ while at the out-patient clinic for a follow-up visit. This was done prior to the mailing of the questionnaires. All care receivers assessed met the inclusion criteria and scored a 2 to 7 on the GOS-E.

Following administration of the GOS-E, the remaining 8 questionnaires (CRCCQ, PCS, CMS, CRSS, ACAS-mv, RCS-mv, FSS-mv and SF-36) were administered to the care receivers. Specific medical information about the care receivers was obtained, by the PI or research assistants, from their respective medical records.

Although data were obtained, via interview, from those who were illiterate (n= 18; 6.2%), subjects who were literate were offered the opportunity to personally complete the questionnaires or to do so via interview. The majority (n = 268; 92.1%) asked to have the questionnaires administered via interview, wherein the PI or research assistants read the questionnaire items and recorded the respective responses. Only 23 (7.9%) care receivers completed the questionnaires via mail. On average, it took about one and one-half hours to complete the

Table 1 Correlation Matrix of Study Variables (N = 291)

Variables 1 2 3 4 5 6 1. CR Function 1 .297** 2. CG Mutuality 3. CG Preparedness .015 .420** -.517** 4. CR Amt Care .074 .117*5. CG Health .203** .158** $.173^{*}$ -.228**1 6. Rewards of Caregiving .070 .533** .530** .025 .116* 1 7. CG Role Strain -.296** -.384** -.290** .363** -.516** -.249**

*p<.05; **p<.01

CG = Caregiver

CR = Care receiver

questionnaires. The completed questionnaires were assigned a code number for the purpose of identification.

Data Analysis: Descriptive statistics were used to analyze the demographic characteristics of the caregivers and care receivers. Assumptions underlying path analysis, including normality of distribution, linearity of relationship, homogeneity of variance and multicollinearity, were determined. The correlation matrix and covariance matrix of variables were analyzed, by PRELIS. Finally, path analysis, using LISERL, was carried out to test the hypothesized model.⁴⁰

Results

Pearson's correlation coefficients were performed to evaluate multicollinearity among variables. The results showed the hypothesized relationships among caregiver role strain, rewards of caregiving and all other study variables were supported (see **Table 1**). Linearity and multicollinearity were checked and found to be satisfactory. Fit indices were within recommended guidelines for the path analysis model.

The hypothesized model, which consisted of four exogenous variables (care receiver functional status, relationship with care receiver, caregiver

mutuality and caregiver preparedness) and four endogenous variables (amount of care activity, caregiver health, rewards of caregiving and caregiver role strain), was tested by comparing the model against the data set, using maximum likelihood estimation in structural equation modeling. Results showed, due to misspecified parameters and poor goodness-of-fit indexes (χ^2 = 21.91, df = 7, χ^2/df = 3.13, p = .003, GFI = .981, AGFI = .905, RMSEA = .086), the hypothesized model did not fit the sample data. Thus, modifications were made, as suggested by the modification indices, until all goodness-of-fitindices were within an acceptable level. The process was performed by eliminating non-significant paths, which were the paths from care receiver functional status to rewards of caregiving ($\gamma = -$ 0.03, p > .05), and rewards of caregiving to caregiver role strain ($\gamma = 0.03$, p > .05). Further, the model was modified by adding two gamma parameters from preparedness to caregiver health (reduced χ^2 =14.54) and from mutuality to caregiver health (reduced $\chi^2 = 9.94$).

In this analysis, the two path coefficients in the hypothesized model still were non-significant, which were the paths from care receiver functional status to caregiver role strain ($\gamma = 0.02$, p > .05) and relationship with care receiver to caregiver role strain ($\gamma = -0.04$, p > .05). Moreover, after adding the parameter from mutuality to caregiver health, which was non-significant ($\gamma = 0.12, p > .05$), the parameter from care receiver functional status to caregiver health turned non-significant ($\gamma = 0.09$, p > .05). Although, all four paths were nonsignificant and the fact their parameter estimations were low, all were kept in the model because of substantive interest, increasing parameter estimations and the best fit indexes ($\chi^2 = 4.75 df =$ 7, $\chi 2/df = 0.68$, p = 0.691, RMSEA = 0.000, GFI = 0.996, AGFI = 0.979). These results indicated the associations between care receiver

functional status and caregiver role strain, care receiver functional status and caregiver health, and mutuality and caregiver health were mediated by the care receiver amounts of care, while the association between caregiver/ care receiver relationship and role strain was mediated by caregiver health.

The final modified model proved to have a good fit with the data ($\chi^2 = 4.75$; df = 7; p = 0.691; RMSEA = 0.000; GFI = 0.996; AGFI = 0.979; $\chi^2/df = 0.68$.). Most of the path coefficients in the modified model were significant at a p-value of 0.001 and had the right direction (see Figure 2). The model illustrated care receiver function had a direct negative effect on amount of care. Care receiver amount of care had a direct positive effect on caregiver role strain, a negative direct effect on caregiver health and mediated the effect of care receiver function on caregiver role strain and health. The caregiver/care receiver relationship had a positive direct effect on caregiver's health, while caregiver's health had a positive direct effect on caregiver's role strain. Caregiver's health mediated the effect of caregiver/ care receiver relationship on caregiver's role strain. Caregiver mutuality had a direct positive effect on amount of care and rewards of caregiving, but a direct negative effect on caregiver role strain. In addition, care receiver amount of care mediated the effect of caregiver mutuality on caregiver health. Caregiver preparedness had a direct positive effect on rewards of caregiving and caregiver health, and a direct negative effect on caregiver strain. However, care receiver functional status failed to demonstrate a significant negative direct effect on caregiver role strain, as well as a significant direct positive effect on caregiver health. Caregiver/care receiver relationship failed to demonstrate a significant direct effect on caregiver role strain and caregiver mutuality failed to demonstrate a significant positive effect on caregiver health.



Chi-square = 4.75; df = 7; p-value = 0.691; RMSEA = 0.000



CG = Caregiver; CR = Care Receiver

For the square multiple correlations (R^2) , 33 % of the variance of care receiver amount of care was accounted for by care receiver functional status and caregiver mutuality. Nineteen percent of the variance in caregiver health was accounted for by care receiver functional status, caregiver/care receiver relationship, caregiver mutuality, caregiver preparedness and care receiver amount of care,

while 46% of the variance in caregiver role strain was accounted for by care receiver functional status, caregiver/care receiver relationship, caregiver mutuality, caregiver preparedness, caregiver amount of care and caregiver health. Finally, caregiver mutuality and caregiver preparedness were the importance predictors, explaining 41% of the variance in rewards of caregiving (See Table 2).

Table 2	Effects of Predictors of Care Receiver Amount of Care, Caregiver Health,
	Caregiver Role Strain and Caregiving Rewards in the Modified Model

	Affected variables											
Causal Variables	CG Amount of Care			CG Health			CG Role Strain			CG Rewards		
	TE	IE	DE	TE	IE	DE	TE	IE	DE	TE	IE	DE
CR Functional Status	595***		595***	.229***	.139***	.09 ^{ns}	258***	276***	.02 ^{ns}			
CG Relationship with CR				.253***		.253***	131**	089***	042 ^{ns}			
CG Mutuality	.247***		.247***	.057 ^{ns}	058**	.115 ^{ns}	244***	.061 ^{ns}	3***	.367***		.367***
CG Preparedness				.17**		.17**	206***	06**	15**	.397***		.397***
CR Amount of Care				.234***		.234***	.411***	.082***	.33**			
CG Health							35***		35***			
R ²		33%			19%			46%			41%	

NS = Non-Significant[;] *p< .05, **p< .01; ***p< .01

CR = Care Receiver; CG = Caregiver, TE = Total Effect; IE = Indirect Effect; DE= Direct Effect

Discussion

The results revealed caregiver role strain was not directly affected by care receiver functional status, but was mediated through care receiver amount of care. This suggests, similar to prior research, the greater the care receivers' impairments and demands for care from the caregivers, the greater the amount of care provided.²⁴ In addition, as feelings of difficulty or increased needs in caring for care receivers occurs, the greater the likelihood for caregiver role strain. This finding is congruent with prior research ^{9, 17, 24, 26} wherein the demands of care on caregivers were found to be determined by care receivers' functional limitations, cognitive deterioration and degree of disturbed behaviors, which, in turn, influenced caregivers' role strain. Moreover, a high number of caregiving hours per week and number of caregiving tasks carried out have been found to be associated with higher levels of caregiver role strain.²⁴

Amount of care was found to be a mediator between the relationship between care receivers' functional status and caregivers' health. TBI survivors' persistent and high levels of disability require constant assistance, along with an enormous expenditure of energy on the part of caregivers. Consequently, caregivers may experience physical fatigue and exhaustion, which can result in a number of health problems.^{26, 27, 29-31} Caregivers, in this study, indicated they had dedicated their lives to providing care to their family members with a TBI at the risk of neglecting their own health.

The findings, that the caregiver/care receiver relationship influenced the perceived health of caregivers and that the health of caregivers was a mediator between the caregiver/care receiver relationship and caregiver role strain, were congruent with prior research.^{6, 24, 29} Caregivers, who were adult children, sisters or brothers of care receivers, tended, in this study, to report better health than did the caregivers who were parents.

Caregiving adult children, sisters and brothers experienced better personal health than caregiving parents and, thus, as suggested in prior research, were more physically able to provide long-term care than were parents.^{17, 24, 29-31} Parents were more likely to have age-associated health problems, which could have made providing caregiving activities, over a long period of time, more difficult.²⁹⁻³¹

Similar to prior research, ^{28, 32} caregivers, in this study, who reported a high level of mutuality tended to provide greater amounts of caregiving activities than caregivers who reported low levels of mutuality.^{28, 32} Mutuality is a connection with or understanding of another individual that facilitates a dynamic process of joint exchange. Since it involves two individuals where delivery of and receipt of care occurs, the act of caregiving is composed of feelings of mutuality.

Caregivers with high levels of mutuality were found, similar to findings of previous studies, ^{9,11,28,32,33} to perceive their caregiving experiences as more rewarding than caregivers with low levels of mutuality. It appears, since the caregivers were confident in their caregiver/care receiver relationships and felt the care receivers were a significant part of their lives, they more readily accepted the responsibilities of the caregiving role and found the caregiving role inherently meaningful. This they perceived as a reward of caregiving.

Consistent with previous research, ^{9-12, 21-24, 28, 32} when caregivers' mutuality was high the presence of caregiver role strain was low. Mutuality is a type of motivational drive that helps caregivers experience enjoyment in their caregiving activities. A sense of mutuality seems to have enabled the caregivers to cope with the demands of their roles and attenuated the likelihood they would consider institutionalizing their care recipient. Relationships lacking in mutuality often lead to psychological discomfort for both the caregiver and care receiver.²²

The caregivers' preparedness was found to have a direct positive effect on caregiver health and rewards of caregiving, and a negative direct effect on role strain. Thus, caregivers, who perceived being prepared for their caregiving roles, reported more rewards of caregiving and less role strain, than caregivers who perceived not being prepared for their caregiving roles. Preparation can contribute to one's ability to perform his/her caregiving role because caregiving preparedness is based on gaining knowledge of an anticipated role. Most caregivers, in this study, indicated they learned their roles of caregiving on the job rather than through any form of formal training. Throughout their caregiving roles, caregivers sought information and learned by way of everyday experiences of caregiving. As a result, they gained confidence in the management of their care receivers' dependencies and problems, which, subsequently, decreased their role strain and increased the rewards they felt from the caregiving experience. Prior research has found caregivers who feel prepared better manage change and extensive learning, resulting in greater life satisfaction and overall quality of life.9, 10, 13, 28, 32-35

For the square multiple correlations of each outcome variable, the modified model accounted for and explained: 33% in the amount of care activity; 19% in caregiver health: 46% of variance in caregiver role strain; and, 41% in rewards of caregiving. The fact 33 % of the variance of care receiver amount of care was accounted for by care receivers' functional status and caregivers' mutuality suggests improving care receivers' functional status and enhancing caregivers' mutuality can make the caregiving situation more enjoyable. This, in turn, can lead to delivery of a higher quality of care. Close affective relationships, involving past and current closeness, shared activities and confiding in one another, has been found to influence caregivers' behaviors regarding care delivery.9, 10

Consistent with previous research, the important predictors of caregivers' health were care receivers' functional status, ^{24, 29} caregiver/care receivers' relationships, ^{29, 30} caregivers' mutuality ^{22, 28}, care receivers' amount of care ^{14, 24, 29} and caregivers' preparedness.^{28, 34}The stressors inherent in TBI caregiving situations, due to care receivers' functional status and amount of care (i.e. lifting, disrupted sleep and fatigue), could have lead to the caregivers' physical illnesses. Since a large proportion of the caregivers were mothers, who could have been contending with age-related health issues, the strenuous work of caregiving could have exacerbated any existing health problems. Feeling prepared as caregivers, having a good caregiver/ care receiver relationship and having sound caregiver mutuality, most likely, increased the caregivers' comfort in the caregiving situation and, subsequently, had a positive influence on their health status.

Similar to prior research, functional status,^{24, 32} caregiver health, ¹⁷ care receiver amount of care, ^{9, 10, 24, 28} caregiver mutuality,^{9, 10, 22, 28, 32, 33} caregiver/ care receiver relationship²⁴ and caregiver preparedness^{9, 10, 28, 32, 33, 35} were found to be significant predictors of caregiver role strain. Functional impairment of care receivers and caregivers' compromised health status, make the provision of care delivery increasingly difficult for caregivers. The higher the number of caregiving tasks and the more hours of care provided may lead to caregiver fatigue, especially if poor caregiver health already exists. Thus, it is no surprise that such a combination of factors ultimately could lead to caregivers' role strain. However, when caregivers perceive high levels of caregiver mutuality, a positive caregiver/care receiver relationship and preparedness, they may feel more confident in performing their caregiving situations and, subsequently, experience decreased role strain.9, 10, 28

Similar to prior research, caregiver mutuality⁷ and caregiver preparedness³² were found to be predictors of caregiver rewards of caregiving. Caregiving, regardless of motivation (bonding, love, compassion or duty), has an underlying moral quality that can result in a feeling of satisfaction about time spent with the care receiver. Because of the extensive amount of time caregivers and care receivers spent together, the intimacy of their roles, most likely, enhanced their bonding experiences and helped improve their relationships. This, in turn, may have led the caregivers to have a sense of accomplishment (reward). In addition, being prepared for the caregiving role, which can result in successful role implementation, also may have led the caregivers to have a sense of fulfillment (reward). Anytime one is well prepared for a role in life, the more positive he/she may feel about what is accomplished.

Conclusions and Recommendations

The study's findings help explain and predict specific causal relationships that exist in regards to caregivers' role strain and rewards of caregiving. The findings suggest that enhancing caregivers' mutuality, preparedness and health may reduce caregivers' role strain, and increase caregivers' perceptions of the rewards of caregiving. Futures studies need to re-examine and expand the model, using TBI care receiver-caregiver dyads from multiple geographic locations throughout Thailand.

Limitations

Due to the use of numerous instruments, in the study, caregivers needed one and a half hours to complete them. This may have proven to be a tiring task for some caregivers. In addition, data were collected either via interview (neurological outpatient clinic or caregivers' homes) or via mailed questionnaires (caregivers' homes). The use of different procedures may have introduced measurement error that could have affected the internal validity in a variety of not necessarily predictable ways. For example, interviews conducted at the hospital had to be performed in the neurological outpatient clinics and were subject to interruptions so care receivers could be on time for their appointments. The caregivers' scores also may have been influenced by their anxiety regarding their respective caregiver having to wait to see their neurologists.

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ความเครียดในบทบาทผู้ดูแลและรางวัลที่ได้รับจากการดูแลของญาติผู้ดูแล ผู้ป่วยบาดเจ็บทางสมอง ในประเทศไทย

นิภาวรรณ สามารถกิจ, สายพิณ เกษมกิจวัฒนา, อรพรรณ โตสิงห์, ธวัชชัย วรพงศธร

บทคัดย่อ: การศึกษาแบบจำลองเชิงสาเหตุนี้มีวัตถุประสงค์เพื่อศึกษาความสัมพันธ์เชิงสาเหตุระหว่างการ รับรู้ของผู้ดูแลเกี่ยวกับความสามารถในการปฏิบัติกิจกรรมของผู้ป่วย ความสัมพันธ์ระหว่างผู้ดูแลและผู้ป่วย ความสัมพันธ์ต่างเกื้อกูล การรับรู้ความพร้อมในบทบาทผู้ดูแล ที่มีผลต่อปริมาณการดูแล ภาวะสุขภาพของ ผู้ดูแล ความเครียดในบทบาทผู้ดูแลและรางวัลที่ได้รับจากการดูแลของญาติผู้ดูแล โดยใช้ The symbolic interactionist perspective of role strain theory และงานวิจัยที่เกี่ยวข้องเป็นกรอบแนวคิดในการศึกษา กลุ่มตัวอย่างเป็นญาติผู้ดูแลและผู้ป่วยบาดเจ็บทางสมอง จำนวน 291 คน ใน 8 จังหวัดภาคตะวันออก เก็บรวบรวมข้อมูลโดยการตอบแบบสอบถามจำนวน 9 ชุด

รูปแบบจำลองสุดท้ายที่ปรับแก้ มีความสอดคล้องกับข้อมูลเชิงประจักษ์ สามารถอธิบายความเครียดใน ับทบาทผู้ดูแล ได้ร้อยละ 46 รางวัลที่ได้รับจากการดูแลร้อยละ 41 ภาวะสุขภาพของผู้ดูแลร้อยละ 19 และ ปริมาณการดแลร้อยละ 33 ผลการศึกษา พบว่าความสามารถในการทำกิจกรรมของผ้ป่วยมีอิทธิพลโดยตรง ทางลบต่อปริมาณการดูแล ปริมาณกิจกรรมการดูแลมีอิทธิพลโดยตรงทางบวกต่อความเครียดในบทบาทผู้ ดแล และมีอิทธิพลโดยตรงทางลบต่อการรับรู้ภาวะสขภาพของผัดแล ในขณะที่ปริมาณการดแลเป็นตัวแปร กลางที่มีอิทธิพลต่อความสัมพันธ์ระหว่างการรับรู้ความสามารถในการทำกิจกรรมของผู้ป่วยกับความเครียด ในบทบาทผ้ดแลและภาวะสขภาพของผ้ดแล ความสัมพันธ์ระหว่างผ้ป่วยและผ้ดแลมีอิทธิพลโดยตรงทางบวก ต่อภาวะสขภาพของผัดแล ภาวะสขภาพของผัดแลมีอิทธิพลโดยตรงทางลบต่อความเครียดในบทบาทผัดแล และภาวะสขภาพของผ้ดแลเป็นตัวแปรกลางที่มีอิทธิพลต่อความสัมพันธ์ระหว่างความสัมพันธ์ของผ้ป่วยและผ้ ดูแลกับความเครียดในบทบาทผู้ดูแล ความสัมพันธ์ต่างเกื้อกูลมีอิทธิพลโดยตรงทางบวกต่อปริมาณกิจกรรม การดแล และรางวัลที่ได้รับจากการดแล แต่มีอิทธิพลโดยตรงทางลบต่อความเครียดในบทบาทผ้ดแล การรับ รู้การเตรียมความพร้อมในการดูแลมีอิทธิพลโดยตรงทางบวกต่อรางวัลที่ได้รับจากการดูแล และภาวะสุขภาพ ของผ้ดแล แต่มีอิทธิพลโดยตรงทางลบต่อความเครียดในบทบาทผ้ดแล ผลการศึกษานี้เสนอแนะว่าพยาบาล ควรตระหนักและเห็นความสำคัญของการประเมินและการส่งเสริมให้ญาติผู้ดูแลรับรู้ความสัมพันธ์ต่างเกื้อกูล ความพร้อมในการดูแล ปริมาณ และภาวะสุขภาพของผู้ดูแล ความเข้าใจในความสัมพันธ์ของตัวแปรเหล่านี้ จะช่วยให้พยาบาลสามารถให้การพยาบาลเพื่อลดความเครียดในบทบาทผู้ดูแลและส่งเสริมให้เกิดรางวัลที่ได้ รับจากการดูแลได้

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คำสำคัญ: ญาติผู้ดูแล ผู้ป่วยบาดเจ็บทางสมอง รางวัลที่ได้รับจากการดูแล ความเครียดในบทบาทผู้ดูแล

ดิดต่อที่: นิภาวรรณ สามารถกิจ, RN, PhD (Candidate) คณะพยาบาลคาสตร์ มหาวิทยาลัยมหิดล ประเทศไทย E-mail: Niphawan@buu.ac.th **สายพิณ เกษมกิจวัฒนา,** RN, DNS. รองคาสตราจารย์ คณะพยาบาลคาสตร์ มหาวิทยาลัยมหิดล ประเทศไทย **อรพรรณ โดสิง**พ์, RN, DNS. ปู้ช่วยศาสตราจารย์ คณะพยาบาลศาสตร์ มหาวิทยาลัยมหิดล ประเทศไทย

สทางกับ กับสุมุทศ บรรงกับ ธ**วัชชัย วรพงศธร**, PhD. รองคาสตราจารย์ คณะสาธารณสุขคาสตร์ มหาวิทยาลัย มหิดล ประเทศไทย