MODEL FOR FAMILY CAREGIVERS' PARTICIPATION IN CARING FOR TRAUMATIC BRAIN INJURED PATIENTS

SOPARN POTAYA

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Soparn Potay
Sqn. Ldr. Soparn Potaya
Candidate

Somchit Hanucharurnkul
Prof. Somchit Hanucharurnkul, Ph.D.
Major-Advisor

A. Chuaprapaisilp
Assoc. Prof. Arphorn Chuaprapaisilp, Ph.D
Co-advisor

Yupapin Sirapo-ngam
Assoc. Prof. Yupapin Sirapo-ngam. D.S.N.
Co-advisor

Prof.Liangchai Limlomwongse
Ph.D.
Dean
Faculty of Graduate Studies

Kobkul
Assoc.Prof.Kobkul Phancharoenworakul,
Ph.D.
Chairman
Doctor of Nursing Science
Faculty of Nursing

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September 13, 2001

Sopam Potay

Sqn. Ldr. Soparn Potaya
Candidate

Somchit Hanucharurnkul

Prof. Somchit Hanucharurnkul, Ph.D.
Chairman

A. Chuaprapaisilp

Assoc. Prof. Arphorn Chuaprapaisilp, Ph.D
Member

Suchin Boonma

Gp. Capt. Suchin Boonma. M.D.
Member

Yupapin Sirapo-ngam

Assoc. Prof. Yupapin Sirapo-ngam, D.S.N.
Member

Assoc.Prof. Kobkul Phancharoenworakul,
Ph.D.
Member

Asst. Prof. Wanapa Sritanyarat, Ph.D.
Member

Prof.Liangchai Limlomwongse
Ph.D.
Dean
Faculty of Graduate Studies
Mahidol University

Assoc.Prof.Kobkul Phancharoenworakul,
Ph.D.
Dean
Faculty of Nursing
Mahidol University

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This participatory action research, based on Orem's General Nursing Theory, aimed to develop the model for family caregivers' participation in caring for traumatic brain injured patients. The participants, 30 nursing staff, 22 family caregivers and 20 brain-injured patients were recruited according to the predetermined criteria in the Neurosurgical Ward at Bhumibol Adulyadej Hospital, Bangkok. Data was collected and analyzed by using qualitative and quantitative research methods.

The findings helped develop a 5 phases-model for family caregivers' participation in caring for traumatic brain injured patients. The model comprised of 4 elements; 1) the phenomenon of family caregivers' participation in patient care that included 5 phases of action: desperately need for reliance, ready for participation, sharing of care, establish self-efficacy before going home, and self support; 2) the promotion of family caregivers' participation in care consists of: providing care to patient and the family caregiver, caregivers' ability development, self-care ability development of the patient and maintain the caring ability of the family caregiver, building self-efficacy, and facilitating the transitional period; 3) factors influencing the dependent care agency included trust and reliability, caring and compassion of the nurses, sharing information among family members and helping each other, caring experience, hope, reflection, support group, and the patient's recovery; and 4) the care outcomes. Five strategies were used to improve nurse caring attitude and behaviors; reflecting on quality of care, providing information and knowledge, role modeling, providing support, and reinforcement. After participating in the model development program, nursing staff and family caregivers perceived and were satisfied with participation in patient care. There was statistically significant differences between before and after receiving collaborative care in patient's recovery. The nurses' roles in promoting family caregiver participation competencies in patient care as well as the positive and negative impact on other care providers were identified.

The findings substantiated Orem's General Nursing Theory, which explains that the dependent care agency can learn and apply knowledge, enables to promote well being to the patients. The finding also consolidated the benefits of promotion family caregivers' participation in patient care. Suggestions concerning the application of this model are to nursing practice, continuing education, health care service and accident prevention. Continuity of care, multidisciplinary research, research network, and cost-effectiveness should be further explored.

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โสพรรณ โพทะยะ : รูปแบบการพยาบาลโดยให้ญาติผู้ดูแลมีส่วนร่วมในการดูแลผู้ป่วยบาดเจ็บที่สมอง (MODEL FOR FAMILY CAREGIVERS' PARTICIPATION IN CARING FOR TRAUMATIC BRAIN INJURED PATIENTS) คณะกรรมการควบคุมวิทยานิพนธ์ : สมจิต หนุเจริญกุล, Ph.D., อาภรณ์ เชื้อประไพศิลป์, Ph.D., ยุพาพิน ศิรโพธิ์งาม, D.S.N. 245 หน้า ISBN 974-04-0746-3

การวิจัยเชิงปฏิบัติการแบบมีส่วนร่วมครั้งนี้ มีวัตถุประสงค์ เพื่อพัฒนารูปแบบการพยาบาลโดยให้ญาติผู้ดูแลมีส่วนร่วมในการดูแลผู้ป่วยบาดเจ็บที่สมอง โดยใช้กรอบแนวคิดทฤษฎีการพยาบาลของโอเร็ม กลุ่มผู้มีส่วนร่วมในการศึกษาประกอบด้วย ทีมพยาบาลจำนวน 30 คน ญาติผู้ดูแล 22 คน และผู้ป่วยบาดเจ็บที่สมองจำนวน 20 คน ซึ่งรับการรักษาที่หอผู้ป่วยศัลยกรรมประสาท โรงพยาบาลภูมิพลอดุลยเดช กรุงเทพมหานคร เก็บรวบรวมข้อมูลและวิเคราะห์ข้อมูลโดยวิธีการวิจัยเชิงปริมาณและเชิงคุณภาพ

ผลการศึกษาพบว่า รูปแบบการพยาบาลโดยให้ญาติผู้ดูแลมีส่วนร่วมในการดูแลผู้ป่วยบาดเจ็บที่สมองประกอบด้วย 1) ปรากฏการณ์การมีส่วนร่วมดูแลของญาติผู้ดูแล 2) การส่งเสริมญาติผู้ดูแลให้มีส่วนร่วมดูแลผู้ป่วย 3) ปัจจัยที่เกี่ยวข้องกับความสามารถในการดูแล และ 4) ผลลัพธ์การดูแล ปรากฏการณ์การมีส่วนร่วมดูแลของญาติผู้ดูแล มี 5 ระยะ คือ ต้องการที่พึ่ง พร้อมมีส่วนร่วม ร่วมดูแล สร้างความมั่นใจก่อนกลับบ้าน และยืนได้ด้วยตนเอง การส่งเสริมญาติผู้ดูแลให้มีส่วนร่วมดูแลผู้ป่วย ได้แก่ ช่วยเหลือผู้ป่วยและญาติผู้ดูแล พัฒนาความสามารถการดูแล พัฒนาศักยภาพผู้ป่วยและพัฒนาความสามารถของญาติผู้ดูแล สร้างความมั่นใจ และอำนวยความสะดวกในระยะปรับผ่าน ปัจจัยที่เกี่ยวข้องกับความสามารถในการดูแล คือ ความเชื่อถือไว้วางใจ ความเอื้ออาทรของทีมพยาบาล ครอบครัวร่วมรับรู้และช่วยเหลือ ประสบการณ์การดูแล ความหวัง การสะท้อนคิดพิจารณา กลุ่มสนับสนุนช่วยเหลือและการฟื้นสภาพของผู้ป่วย ภายหลังได้รับการดูแลตามรูปแบบการพยาบาลผู้ป่วยมีระดับการฟื้นสภาพดีขึ้นอย่างมีนัยสำคัญทางสถิติ ทีมพยาบาลและญาติผู้ดูแลรับรู้และพึงพอใจต่อการมีส่วนร่วมดูแลผู้ป่วย และทีมสุขภาพที่เกี่ยวข้องได้รับผลกระทบทั้งด้านบวกและด้านลบ ผู้วิจัยใช้กลวิธีในการปรับเปลี่ยนทัศนคติและพฤติกรรมการดูแลของพยาบาล คือ การกระตุ้นให้เข้าใจในสถานการณ์ที่เป็นอยู่ การให้ข้อมูลความรู้อย่างต่อเนื่อง การทำเป็นแบบอย่าง การสนับสนุน และการเสริมแรง

การวิจัยครั้งนี้แสดงความชัดเจนของบทบาทพยาบาล ในการส่งเสริมญาติผู้ดูแลให้มีส่วนร่วมดูแลผู้ป่วย และสนับสนุนความตรงของทฤษฎีการดูแลตนเองที่อธิบายถึง ความสามารถในการดูแลสมาชิกผู้พึ่งพาว่าสามารถเรียนรู้และพัฒนาได้ รวมทั้งชี้ให้เห็นประโยชน์ของการส่งเสริมญาติผู้ดูแลให้มีส่วนร่วมดูแลผู้ป่วย พร้อมกันนี้ผู้วิจัยได้เสนอแนะการนำรูปแบบนี้ไปใช้ในการปฏิบัติการพยาบาล การจัดการศึกษาต่อเนื่อง การบริการด้านสุขภาพ และการป้องกันอุบัติภัย รวมทั้งการศึกษาติดตามผลลัพธ์การดูแลในระยะยาว การวิจัยแบบสหวิทยาการ การสร้างเครือข่ายเพื่อการวิจัย และความคุ้มค่าในเชิงเศรษฐศาสตร์สาธารณสุข ต่อไป

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CHAPTER I

INTRODUCTION

Background and Rationale of the Study

Traumatic injury is a major health issue and is the secondary leading cause of death in Thailand. The economic impact on entire injuries has not been estimated. The largest cause of death resulting from motor vehicle crashes cost approximately 60 to 90 billion baht in 1993 (Directing Committee on Public Health Development Plan, 1996). Multi-traumatic injuries usually involve some degree of brain injury, so traumatic brain injury is a major cause of deaths.

The department of Public Health Statistics reported that 11,113 people died of brain injury and 174,344 individuals suffered from traffic traumatic brain injury and required medical management in the year 1992 (The Neurosurgical Association of Thailand, 1997). Male adolescents and young adults are the most at risk group from a motor vehicle accident, which is the predominant cause of injury (Assawapat, 1996; Kijmahatrakul, 1999; Promkuntong, 1997; Tangchitvittaya, 1999; Tepahudee & Phuenpathom, 1999). Recent medical advances on brain injury have contributed to highly significant rate of survival. However, many survivors survive with cognitive, behavioral and physical impairment, preventing them to return to normal life. Long-term rehabilitation and continuity of care during and after hospitalization are also.

However, long-term rehabilitation and continuity of care provided by health care professional in institutional settings hardly exist. Current health care climate and economic incentive focus on shortening the length of hospital stay. The patients are moved out of an acute care setting, and discharged from the hospital as quickly as the doctor find appropriate medical conditions. Traditional biomedical model of health care regard consumers as passive care recipients. This model of care may obstruct the promotion of caregiving sufficiently and continuously. But the concept of family participation encourages families to actively involve in health care of their relatives. Therefore, it can be said that this measure is an important alternative for the patients who have been hospitalized. Much nursing research literature has reported valuable and vast benefits of family participation in patient care (Ashworth, et al., 1992; Jewell, 1994).

Bhumibol Adulyadej Hospital, a teaching tertiary care hospital of the Royal Thai Air Force, annually admits more than 200 severely traumatic brain injured patients. The hospital, therefore, attempts to improve quality of care for traumatic brain injured patients by applying the idea of family participation. The project of family participation in patient care aims at meeting family caregiver's needs, improving care abilities, and diminishing dissatisfaction. The project may result in improving patients' health care and patients' recovery, reducing length of hospital stays, decreasing the cost of long-term care and the loss of income on the part of both survivors and caregivers, and decreasing health care national expenses. Furthermore, it maximizes family readiness and competence with learning and continuity of care following hospital discharge.

Traditionally, an application of family participation concept to nursing practice appears ambiguous. Since a large number of critically brain injured patients require complex, hasty and continuity of care, the main provision of care involve physical care, and management of the physician's treatment plans with little involvement in the patients' daily living activities that are provided by their relatives. A training program for relatives is informally learned and occasionally arranged. Most teaching methods and information are used for clinical learning and skill training. Detailed information on how family can be more closely involved in patient care is not mentioned. Professionally autonomous nursing staff and family member interaction is task-orientated, superficial and routine. Their traditional attitudes and routine practice prevent them from the progress towards caring participation equally. In addition, family caregivers might be either too shy or too insecure to approach nursing staff. They are afraid that they might even disturb nursing personnel. Thus, most of the family caregivers obtain knowledge and skill to care for the patients by self-learning. They learn from self-awareness, past caregiving experience, observation of the acts of health care personnel and other family caregivers, trial and error practice and information seeking. Some family caregivers are not concerned, and lack appropriate participation in the caregiving process. A quarter of these patients experience complications during hospitalization, and a half is discharged from the hospital with varying degrees of disability. It is therefore suggested that clinical research on model development for family caregivers' participation in caring for recovery of traumatic brain injured patient is needed to develop their abilities to care for the patients at home.

Review of previous studies showed that most research focused on families experience, needs, and effective intervention programs to support relatives of head injured patients (Acorn, 1993, 1995; Baker, 1990; Campbell, 1988; Engli & Kirsivali-Farmer, 1993; Grant & Bean, 1992; Hall, et al., 1994; Johnson, 1995; Mathis, 1984). Additionally, a study investigating information on training benefit in experimental animals following brain damage was conducted (Yu, 1976). Based on this experiment, the human studies demonstrated that active, timely, and appropriate rehabilitation program led to functional recovery improvement in brain damaged patients (Cope & Hall, 1982; LeWinn & Dimancescu, 1978). As a matter of fact, the previously mentioned program has theoretical underpinning of coma stimulation programs rather than the existing traditional rehabilitation (Ansell, 1991; Baker, 1988).

Numerous information describes the brain injured rehabilitation program, which is managed by a multidisciplinary team and family involved in a critical and rehabilitation area (Baggerly, 1986; Bottcher, 1989; Brillhart & Stewart, 1989; Hall, et al., 1992; DeYoung & Grass, 1987; Grinspun, 1987; Perry, 1983; Richmond & Craig, 1986; Sosnowski & Ustik, 1994). The effects of rehabilitation programs were reported in a controlled study by Kater (1989), and Mackey and colleagues (1992), who indicated that the formalized rehabilitation programs reduced coma duration and length of hospital stays.

As previously reported, those researchers regarded family involvement as an integral part of the rehabilitation team. The major emphasis was greatly pointed at the treatment, which were controlled studies and manipulated by the researchers with knowledge professionals know best and with the families playing a passive role. The findings were unclear whether family involvement in care was active participation. There was no evidence to support whether family caregivers who had taken part in care met their needs, and satisfied with the role they played in patient care.

Intorn's study (1996) reported the effects of a comparison of two groups of head injured patients with and without relatives' involvement. The results revealed that the group of patients with relatives' involvement had less complication than those with no involvement. It was also shown that there was no statistically significant difference on functional recovery, length of hospital stay, and relatives' satisfaction with care between the study and the control groups. The degree of family caregivers' participation in care was one issue which the researcher considered within this context. The obvious factors influencing the degree of participation concerned with socioeconomic factors and organizational structure (Arnantapunpong, 1995; Suwanno, 1997). They are important since the environmental factor should facilitate their choice to participation. The staff's attitude and hospital policy are the key factors to encourage family caregivers to participate in patient care (Sharp, 1990).

Family caregivers' participation require greater understanding of both the nursing concept and practice that can lead to effective interventions to encourage and support family caregiver participation. To increase their participation, relevant information about the possibilities to take part in planning, decision making and evaluation of care between family caregivers and nursing staff are needed for their information. Also, a flexible approach to planning and implementing participation in care is required.

Nursing studies indicated that empowering and collaborative nature of participatory action research could also contribute to the increase of self-care abilities and patients' satisfaction with care (Hanucharurnkul, et at, 1995; Keeratiyutawong, 1994; Nantachaipan, 1996; Wattana, 1997) and the promotion of caregivers' caring competencies (Hirunchunha, 1998). The studies pointed at the understanding process of development, influencing factors, method of appropriate provision, and limitation. An investigator serves as a facilitator of the process to allow the participants to take an active and collaborative role in all phases of the research project (Soltis-Jarrett, 1997). It also transforms the subject-object relationship of traditional science into a subject-subject relationship (Reason, 1994). Evidently, participatory action research gives power to family caregivers and nursing staff by allowing them to construct and use their own knowledge, and produce knowledge and useful action that allow them to implement sustained changes in the structure of existing system for themselves (Small, 1995).

Therefore, this study is aimed at the model development by collaboration with family caregivers and nursing staff. The investigator expects that the need of the participants will be met, which will increase their satisfaction and ultimately promote optimum recovery for the individuals with traumatic brain injury. Finally, the study will contribute additional knowledge to the theoretical body of knowledge concerning family caregivers, and also extend the theoretical ideas to empirical testing through a participatory action research approach that leads to a new trend of health care provision in the institution for Thai society.

Purposes of the study

The general purpose of the study is to develop the model for family caregivers' participation in caring for traumatic brain injured patients in the hospital.

This study specifically aimed at:

1. describing the collaborative process to develop the model between nursing staff and family caregivers;
2. exploring factors influencing the collaborative process;

3. determining the family caregivers' perceptions and satisfaction with participation in patient care;
4. determining the nursing staffs' perceptions and satisfaction with participation in the program;
5. determining the change in recovery levels of traumatic brain injured patients who have received the participated caring model; and
6. exploring the impacts of the model on other care providers.

Conceptual framework

Orem's General Nursing Theory was used as a framework in this study. The participatory action research approach was utilized as a methodological basis to develop the model for family caregivers' participation in caring for traumatic brain injured patients.

Orem's General Nursing Theory

Orem's General Nursing Theory is expressed in three theoretical elements: theory of nursing system, theory of self-care deficit, and theory of self-care (Hanucharurnkul, 1991; Orem, 1995; Taylor, 1989). In describing theoretical elements, a nursing system is the action system designed and produced by nurses. The nurse performs it in collaboration with the patient to know and meet the patient's therapeutic self-care demands and to protect, to regulate the exercise or development of the patient's self-care agency. As for elaboration of the theory of self-care, self-care is a regulatory function of mature human beings. There is the practice of deliberate actions that the person initiates and performs to meet his or her own self-care requisites. Included in the concepts of this theory are therapeutic self-care demand and self-care agency. Therapeutic self-care demand is the total actions the person needs to maintain health, while self-care agency is the capacity of the person to engage in the estimation, decision making and production operation of self-care. When the demand of actions for self-care exceeds the person's capacity to act, because of health-related factors, a self-care deficit exists and the need for nursing can be established. Dependent care is the care the members of social groups provided for other persons who are dependent due to age, developmental state, or health states, and who are unable to provide the care for themselves.

Traumatic brain injury has profound effects on cognition, behavior and physical body of the survivor. These preclude survival capabilities on making decision and practice the deliberate action. As a result, the survivor requires care from others. In family structure, the members such as parents, children, or spouse of the patient will be a responsible person to care for him. This complex ability should be performed to care simultaneously for the patient and the caregiver himself or herself. Evidence from various literature supported that the family caregiver experiences taken during a critical and rehabilitation area change the family caregiver abilities, routine daily life, marital relationships, money management and social activities. The entire changes can lead to increased stress, fatigue and burden within the families (Acorn & Roberts, 1992; Frye, 1987; Hall, et al., 1994; Kreutzer, et al., 1992; Livingston, et al., 1985a, 1985b). The situations also affects family caregivers' capabilities on self-care and dependent-care. These can be expressed in term of self-care deficit. When the family caregivers are unable or unwilling to provide the necessary care, nursing need may come to play a role.

Nursing is the practice of deliberate action. Nurses provide nursing care to family caregivers and their dependents who require it. The nurse acts in collaboration with family caregivers to reduce dependent care deficit and increase dependent care agency. The nursing services demand societal, interpersonal and professional-technologic orientation. In helping situations, five helping methods are often used. There are action for another, guidance and direction, provision of physical or psychological support, provision and maintainance of environment to support personal development, and teaching method. Nurses use either or all of the methods or a combination of them, in relation to the action demands of persons under nursing care and their health-associated action limitation (Orem, 1995).

However, a long traditional biomedical model and hospital policy generally limit participation in in-patient care and preparation for continuity of care predischarge by family caregivers. In a hospital setting, patients and families are regarded as passive recipients of care. Health care professionals often lack training in sharing control and power with patients and families. Family caregivers' participation in caring for patients therefore may be more difficult to implement. Thus, a flexible approach to planning and implementing participation in care is required.

Participatory action research

Participatory action research (PAR) is a research method of carrying out studies in critical science. Critical social theory virtual reality is assumed to be apprehendable which was once plastic, but which was, over time, shaped by social, political, cultural, economic, ethnic, and gender value factors focusing on changes and conflicts of social relations or institutions (Guba & Lincoln, 1994). It aims at empowering people, especially less powerful people and oppressed groups, to gain equality (Neuman, 1997; Small, 1995). It therefore transforms the subject-object relationship of a traditional medical model into a subject-subject relationship (Reason, 1994), thus empowering people to have more autonomy and control over their own health care (Webb, 1991).

Participatory action research is a research method in which a group of people come together to work on a thematic concern through the self-reflective spiral: a spiral of cycles of planning, acting, observing, reflecting, and then re-planning (McTaggart, 1991; Reason, 1994). The most central feature of the participatory action research is the participation of participants in the research process. The participants are full partners in the research process, while the researcher serves as a facilitator of the process (Small, 1995; Soltis-Jarrett, 1997; Webb, 1991). The participatory action research intends to produce knowledge that can change individuals and culture of the groups, institutions, and societies to which they belong. These are viewed as a process for personal empowerment, emancipation, and social transformation, which mean that the political change can be achieved and sustained.

Participatory action research is well suited for this study because it will assist participants to better understand the research process that requires a collaboration between family caregivers and nursing staff in sharing information; determining dependent care demand, dependent care ability and dependent care deficit; exploring the problem and influencing factors; and self-discovering of appropriate actions in order to promote dependent care abilities. When the interaction between nursing staff and family caregivers occurr, the participants may rely on the situation they are dealing with. They may have determination to perform care for the patients as it has been described in Orem's theory as deliberate action. As for the care provider, there is a strategy to maximize caregivers' competency to provide effective care to patients and caregivers themselves in both institutional setting and continuity of care at home.

Scope of the study

The participatory action research (PAR) approach was used to develop the model for family caregivers' participation in caring for traumatic brain injured patients. The Neurosurgical Ward, the 6th floor of Kumklao Building, Bhumibol Adulyadej Hospital, Directorate of Medical Service of the Royal Thai Air Force was a setting for the study.

Definition of terms

1. **Model for family caregivers' participation in patient care** refers to the model which relies on collaborative process between nursing staff and family caregivers of traumatic brain injured patients during hospitalization through the critical process of observation, reflection, and transformation.

2. **Patient recovery** refers to the optimum awareness and functional level of traumatic brain injured patients following management. These were assessed by using 1) the Modified Disability Rating Scale, 2) Complication Inventory Tool, and 3) length of hospital stay.

2.1 **Modified Disability Rating Scale** is the level of awareness and self-care functioning developed from the combination of the Rappaport Disability Rating Scale within 3 categories and the Functional Independence Measure. The measurement consist of (1) arousal and awareness, (2) cognitive ability to handle self-care functions, and (3) physical dependence upon others.

The range of possible score is between 7 and 33, with the higher scores indicating the higher ability.

2.2 **Complications** are defined as signs and symptoms which have no direct effect from traumatic brain injury at the time of study enrollment until the patients are discharged from the hospital. Complications are assessed by the Complication Inventory Tool within 4 categories: respiratory infection, urinary infection, pressure sore, and contracture. These are assessed by using the patient's clinical manifestations, physical examination, and laboratory diagnostis, as follows:

2.2.1 Respiratory infection:

(1) new chest x-ray shows lung pathology such as infilltration, consolidation, cavitation, or pleural effusion, and

(2) two out of four clinical manifestations and diagnostic examinations are shown as: (a) fever (T ≥ 38°C); (b) productive cough with greenish or rusty spots; (c) crackles or crepitation, and/or dullness over area of consolidation; and (d) leukocytosis: WBC > 10,000 cell/mm with neutrophil > 80%.

2.2.2 Urinary infection:

(1) fever (T ≥ 38°C) and/or pressing pain at supra-pubic area;

(2) urinalysis: white blood cell count ≥ 10 WBC/ high-power field, and/or urine culture: bacteriuria ≥ 10^5 colonies/ml.

2.2.3 Pressure sore is localized damage to the skin which is caused by disruption of blood supply to the area, usually caused by pressure, shear or friction, or a combination of any of these. It is assessed by the American National Pressure Ulcer Advisory Panel (1989) considered initial stage II and beyond.

Stage II: Partial-thickness loss involves epidermis and/or dermis. The ulcer is superficial and may be seen as a blister, abrasion or crater.

Stage III: Full-thickness wound involves epidermis, dermis and subcuticular layer. The ulcer shows as a crater with or without undermining.

Stage IV: Extensive destruction involves other tissues such as muscle, tendon or bone.

2.2.4 Contracture is deformities resulting from both persistent lack of motion and active nonfunctional posturing.

2.3 **Length of hospital stay** refers to the number of days the patient stays in the hospital after admission until he or her is discharged from the hospital.

3. **Traumatic brain injured patients** refer to Thai patients aged at least 13 years who sustain traumatic brain injury and receive treatment in the hospital.

4. **Family caregivers** refer to family members, relatives or significant persons who give direct care to the patient most of the time during hospitalization.

5. **Family caregiver's preference in participation** refers to the needs of family caregivers who deal with the participated caring process. The caregiver's needs is measured by the 30-item of the Family Caregiver's Preference in Participation Questionnaire consisting of five dimensions: information seeking, decision making, negotiation, caring practice, and evaluation of care. The total scores of the scale range between 30 and 120, with a higher score indicating higher needs in participation.

6. **Actual participation of family caregiver** refers to actual participation of family caregivers who deal with participated caring process. The actual participation is measured by the 30-item of the Family Caregiver's Actual Participation Questionnaire consisting of five dimensions: information seeking, decision making,

negotiation, caring practice, and evaluation of care. The total scores of the scale range between 30 and 120, with a higher score of the scale indicating higher actual participation in patient care.

7. **Family caregivers' satisfaction with participation in patient care** refers to satisfaction of family caregivers who deal with participated caring process. The satisfaction is measured by the 30-item of the Family Caregiver's Satisfaction with Participation in Patient Care Questionnaire consisting of five dimensions: information seeking, decision making, negotiation, caring practice, and evaluation of care. The total scores of the scale range between 30 and 120, with a higher score of the scale indicating higher satisfaction with participation in patient care.

Significance of the study

1. This study will produce a model for family caregivers' participation in caring for traumatic brain injured patients in the hospital. The model can be a guideline for directive action providing quality care for traumatic brain injured patients hospitalized in Bhumibol Adulyadej Hospital. It will lead to a new trend of care providers in the institution through a collaborative process between nursing staff and family caregivers. The model will also help the participants meet their needs, increase satisfaction and promote optimum recovery for the traumatic brain injured patients.

2. The study provides practice theories specific to caring of traumatic brain injured patients in the hospital, and changes the traditional nursing model. The study was conducted based on a theoretical idea of Orem's General Nursing Theory and implemented for clinical nursing practice of traumatic brain injured patients on the

neurosurgical ward through participatory action research approach. The model can be used to determine goal and practice guideline to improve clinical nursing practice. The structural components of the model include: definition of clients' situation, nursing therapeutics, process by which therapeutics is implemented, patterns of desired status or consequences, and context for desired / undesired status and for therapeutics.

3. The study extend theoretical ideas of dependent care agency derived from Orem's General Nursing Theory to empirical testing within institutionalization through participatory action research approach.

4. The study also attempts to close the gap between theory, research and practice, and to help participants assess problems, design action plans and implement actions in the practice situation for themselves.

CHAPTER II

LITERATURE REVIEW

A review of theoretical and empirical literature are presented in 7 consecutive themes. First, impacts of traumatic brain injury on the survivors is introduced. Second, impacts of traumatic brain injury on the survivor's families and society are described. Third, needs of care and rehabilitation of traumatic brain injured patients is explained. Fourth, needs of family caregivers at immediate care and hospital discharge plan are illustrated. Fifth, family members as caregivers—a concept of dependent care agency in Orem's theory—is discussed. Sixth, a traditional approach to brain injured patients and their families is described. Finally, alternative care is discussed. The reviews are utilized to help conceptualize and provide a basis for a structural model.

The impacts of traumatic brain injury on the survivors

Traumatic brain injury results from two mechanisms of head injury: a moving object against a stationary head, and the head in motion strikes an immobile structure (Bunyaratavej, 1983; Connolly & Zewe, 1981). Head injury can create focal and diffuse brain damage from initial impact and secondary brain damage. Initial impact damage may take the form of contusion of the gray matter, laceration, and diffuse white matter lesions. Secondary brain damage includes raised intracranial pressure, intracranial hematoma, diffuse brain swelling, and ischemic brain damage (Bottcher, 1989; Habermann, 1982). Focal or diffuse brain damage, occurring initially and secondarily, leaves the survivor with physical, behavioral, psychological, or cognitive impairment. The degree of disabilities of the brain injured patients vary according to 1) severity of brain injury, and 2) the area involved.

1. Severity of brain injury

Severity of initial injury is crucial to an investigation of patient ability to predict outcome and medical orientation. The most commonly used and internationally accepted standard for assessing depth of coma in traumatic brain injury is the Glasgow Coma Scale (GCS) (Teasdale & Jennett, 1974). The scale identifies responsiveness in three modalities: eye opening (1-4 scores), best verbal response (1-5 scores), and best motor response (1-6 scores). With a maximum score of 15, a patient awakes, orients and obeys commands. The lowest score of 3 indicates deep unconsciousness with flaccid limbs. The scores of 13 to 15 are defined as mild brain injury, while the scores of 9 to 12 are defined as moderate brain injury, and 3 to 8 indicate severe brain injury.

The injured patients with moderate and severe brain injury require hospitalization, just like the patients who sustain mild brain injury and have physical manifestations reflecting possible severity of injury and life threatening (The Neurosurgical Association of Thailand, 1997). The majority of the patients are male adolescents and young adults who suffer from motor vehicle accidents. Severe brain injury affects a large number of brain injured patients. Many authors have noted that 44-52 percent of the patients die after sustaining severe brain injury (Kijmahatrakul, 1999; Tangchitvittaya, 1999; Tepahudee & Phuenpathom, 1999).

Several documents have exposed the relationship between outcome and the Glasgow Coma Scale. Jones (1981) has cited the outcomes of severe brain injuries in three studies. The report has indicated that a patient with a CGS of 8 or less has a 28-49 percent chance of dying, and a 39-60 percent chance of achieving a good or moderate recovery. Jennett and others (1979 cited by Contant and Narayan, 1996) noted that patients with a GCS of 3-4 during 24 hours postinjury have a 87 percent chance of being in vegetative state or dead, whereas those patients with a GCS of 11-15 have only a 12 percent of vegetative state or dead. Many studies also demonstrated that one of the most consistent predictors of outcome following brain injury is the patient's age. The findings revealed that mortality increase with increasing age.

2. The area involved

The local effect of the area involved may take part in cognitive, behavioral and physical manifestations of brain injury as follows (Baggerly, 1986):

2.1 Cortical involvement

The characteristics of patients who have sustained frontal injuries include personality change, euphoria or apathy, lack of insight, lack of social graces and inability to monitor self. Emotional responses are inadequate for the situation at hand, and lack of initial and goal-directed behavior may also be seen. Other manifestations that may arise with frontal damage are poor problem solving, difficulties in shifting from one concept to another and perseverance, and verbal or physical repetition of some word or action.

Many sensory and sensory integration functions are altered when the parietal lobe is damaged. Involvement of the dominant hemisphere results in aphasia and apraxic problems, skilled movement deficits, and decrease analytical and logical reasoning powers. On the other hand, nondominant hemisphere damage may cause visual-perceptual and spatial problems, agnosia, and loss of prosody or melody of voice.

Temporal lobe damage can produce a variety of responses, such as anxiety, calmness, rage, aggression, and depression. These are not associated with circumstances in the external environment but are triggered by internal mechanisms.

Hippocampus, the structure associated with recent memory located on medial temporal lobe, is frequently damaged. Immediate memory is generally impaired because it depends on the ability to interact with environment, that is, to attend to, perceive, and process input, which requires comprehension, attention, and concentration skills. Remote memory is linked to many association areas of the cortex. Lack of memory is a key issue because teaching/learning interactions cannot occur in the absence of short-term memory skills.

Emotional and behavioral changes can occur with damage to medial cortical regions in a part of the limbic system. Diffuse white matter injury is associated with altered consciousness and may be responsible for the arousal and attentional skill problems seen following closed head injury.

2.2 Subcortical structures

Subcortical structures are associated with basic functions. When hypothalamus is damaged, it results in autonomic nervous system disturbances, and fluid and electrolyte imbalance. Appetite and sleep-wake cycles are disrupted. Mood swings, irritability, and listlessness can also occur.

Posturing often seen in the acute results from midbrain and brain stem damage associated with rotational injuries. Essentially, an imbalance between the cortical fibers is responsible for extension and flexion of muscle groups. Decorticate posturing reflects a loss of input from fibers inhibit flexion, while decerebrate posturing indicates a loss of fibers inhibit extension and an excess of fibers facilitate extension. Severe shearing injuries in the areas of the brain stem may result in a vegetative state, in which basic life functions return, including eye opening and sleep-wake cycles, but cognition is absent.

Furthermore, involvement of pons may produce equilibrium and balance problems. Respiratory and cardiac embarrassment results from medulla damage. Pupillary changes, decreased corneal reflex, extra-ocular involvement, facial paralysis, chewing difficulty, dysarthria, phonation deficit, decreased airway protection, and swallowing problems occur with the cranial nerve involved. Basal ganglia damage is associated with movement disorders, such as tremors and dyskinesia, while ataxia is often seen with cerebellum damage.

In summary, overall functioning and performance are a reflection of the left and right hemispheres of the brain working together, and in conjunction with subcortical and brain stem structures. Head injury resulting in both focal and diffuse damage can affect performance ability and alter social functioning of the injured patients. Severity of initial injury and local effect of the area involved are therefore crucial to determine the outcome and medical orientation.

The impacts of traumatic brain injury on the survivor's family and society

1. The impacts of traumatic brain injury on the survivor's family

Comparing with other illnesses, brain injury is considered as the illness that creates long-term effects on patients and families' lives. Traumatic brain injury affects not only the survivor, but also the survivor's family. The traumatic event and subsequent hospitalization increase stress within the family. When a traumatic injury occurs, the family is confronted with multiple stressors. These stressors include a sudden onset without warning, unfamiliar hospital environment and unfamiliar professional staff, separation of family members, an uncertain prognosis, and a potentially overwhelming financial burden (Braulin, et al., 1982; Mauss-Clum & Ryan, 1981; Rogers & Kreutzer, 1984). The level of stress which family members experience also depends on the following factors: (1) the sudden and unpredictable nature of trauma, (2) nature of relationship of the specific family member to the trauma victim, (3) the issue of responsibility, guilt and anger, (4) religious beliefs, and (5) trauma sequel and impact on the family system (Solursh, 1990).

Stress may reduce family's ability to take and comprehend information, ability to maintain family functions, and utilize coping skills. Family members who experience stress may be unable to comply with hospital regulation or may distrust hospital personnel (Elliott & Smith, 1985; Testani-Dufour, et al., 1992). The family members may experience anxiety since the immediate post injury period until the patients are transferred from intensive care units to step down or rehabilitation units (Bokinskie, 1992).

After hospital discharge, family members deal with the patients' personality and behavioral changes. Living with individuals who have developed personality and behavioral changes is rather distressful than living with the ones who have developed intellectual or motor changes. Frustration, irritability, annoyance, depression, and anger are common personal reactions reported by wives and mothers of the brain injured patients (Mauss-Clum & Ryan, 1981). Evidence from several studies has revealed that level of stress is related to the personality changes that occurr in the survivor and to the caregivers' perception of the symptoms (Hall, et al., 1994). Social dysfunction (Livingston, et al., 1985b), altered family roles and relationships (Acorn & Roberts, 1992; Livingston, et al., 1985a), and financial strain (Hall, et al., 1994; Rogers & Kreutzer, 1984), in combination with the long recovery process, may create extreme burden in the family. Livingston and colleague (1985a, 1985b) stated that the first year at home after the injury is the burden and distress for the caregivers. Caregivers' self-perceived burden remains relatively constant through the first year and then decreases during the second year postinjury (Hall, et al., 1994).

Disabilities result from brain injury, family members therefore have to adopt new roles and expand their responsibilities. Mothers and wives are persons who can well adapt to these new roles (Acorn, 1993; Bokinskie, 1992; Campbell, 1988; Grant & Bean, 1992). Studies have demonstrated that spouses suffer more from being caregivers than parents (Hall, et al., 1994; Mauss-Clum & Ryan, 1981). Hall and colleague (1994) pointed out that the parents cope better than spouses because parental caregivers are pursuing a former role, but spouses are pursuing a new role. Spouses have to cope alone with the burden, whereas parents could share and support each other regarding available and financial problems. In contrast, the study of Levingston and others (1985a, 1985b) revealed that there are no statistically significant differences between wives and parents in perceived burden at 3, 6 and 12 months after the injury.

Haberman (1982) stated that most of the problems the families of brain injured individuals encounter could not be removed, but manageable. Families could be helped to readjust their expectations, given practical advice for management of the individual, and helped to realize their own needs and responsibilities. Mathis (1984) suggested that meeting families' needs could reduce their stress. Thus, it is important to assess the family is needs and determine their needs for additional support.

2. The impact of traumatic brain injury on society

As previously mentioned, the majority of persons sustaining traumatic brain injury are young men who are in the prime life and one productive human resources for family, community and the nation. The results from traumatic brain injuries leave the survivors with cognitive, behavioral and physical impairment. The residual deficits preclude their return to normal life, and alter the human resources who contribute to family and society to become dependent, especially in those who have suffered severe brain injury requiring long-term rehabilitation and continuity of care during hospitalization and after hospital discharge. Brain injury therefore accounts for a major economic impact by reducing the productive workers.

The cost of individual's suffering and economic impact on entire traumatic brain injury is immense and it concerns the cost of hospitalization and rehabilitation therapy for the brain injured patients as well as the loss of earning incomes on the part of both survivors and caregivers. In the United States, the national medical bill for brain injuries was estimated at $9-$12.5 billion in 1982 (cited by Testamni-Dufour, et al., 1992). Delodes (1979 cited by Tanmukyakul, 1991) proposed a calculable cost of injuries that 6 percent of the cost is the loss of properties, 25.3 percent is the expenses from death, and 68.7% of the largest cost is the expenses on medical bill and salvage disable persons. In Thailand, the cost of entire traumatic brain injuries has not been calculated. The economic impact on death resulting from motor vehicle crashes costs approximately 60 to 90 billion baht which was 16.5 percent of the whole goverment budget in 1993 (Directing Committee on Public Health Development Plan, 1996).

Needs of care and rehabilitation of traumatic brain injured patients

Brain injury is an extremely common illness with long-term sequel, so the need of care is not required only during the acute phase but also from the time of injury throughout the rehabilitative phase of recovery. Immediately after the injury, the patients require a rapid and accurate diagnosis of primary injuries and early aggressive treatment to prevent secondary brain insults such as hypoxia, hypercapnia, hypotension, and intracranial hypertension (Marshall, et al., 1990). Uncontrolled intracranial hypertension is the most common cause of severe morbidity and mortality in the brain injured patient. To preserve the homeostatic brain and prevent secondary injuries, all therapies are directed toward these goals, including removal of mass lesions, ventilation support, control of intracranial pressure (ICP), seizure prophylaxis, maintenance of fluid and electrolyte balance, and nutritional support (Ammons, 1990; Bowers & Marshall, 1982; Marshall, et al., 1990).

Once the secondary problems are under control, the patients' condition may become stable. Brain injured patients require care according to the degree of impairment remaining from brain injury. Physical problems, coma, and paralysis are commoning found in the severe brain injured patients. Prolonged inactivity and permanent physical limitations lead to complications including contracture formation, pressure sores, respiratory infection, and urinary tract infection. To avoid such consequences, preventive rehabilitation including skin protection, contracture prevention, and patient activation have evolved. When there is permanent impairment, additional therapeutic procedures are required to optimize residual ability (Perry, 1983). Physical manifestations may subside long before behavioral and cognitive problems. Cognitive and behavioral changes induce an obstacle to patients' capability to perform activities. However, appropriate rehabilitation programs may provide the brain injured patients to maximize their ability.

A contextual basis for effective brain injury rehabilitation is offered by the Levels of Cognitive Functioning Scale (LCFS) (Hagen, Malkmus and Durham, 1979). The scale was developed and validated by the Professional Staff Association of Ranchos Los Amigos Hospital, Inc., in California. It was designed as an assessment tool for existing cognitive abilities and as a basis for delineating treatment approaches to increase cognitive abilities of the patients. The scale describs eight levels of cognitive function as demonstrated through behavioral changes: level I no response; level II generalized response; level III localized response; level IV confused, agitated and inappropriate response; level V confused, non-agitated and inappropriate response; level VI confused but appropriate response; level VII automatic and appropriate response; and level VIII purposeful and appropriate response. The details of each level are described as follows:

level I no response

(a) complete absence of observable change in behavior when presented with visual, auditory, or painful stimuli

level II generalized response

(a) demonstrate generalized reflex response to painful stimli

(b) respond to repeated auditory stimuli with increased or decreased activity

(c) respond to external stimuli with physiological changes

level III localized response

(a) demonstrate withdrawal or vocalization to painful stimuli

(b) turn toward or away from auditory stimuli

(c) blink when strong light crosses visual field

(d) follow moving object passed within visual field

(e) respond to discomfort by pulling tubes or restraints

(f) respond inconsistently to simple commands

level IV confused – agitated

(a) alert and in heightened state of activity but demonstrate severely decreased ability to process environment; respond primarily to own internal agitation

(b) perform motor activities but behavior essentially nonpurposeful relative to environment

(c) demonstrate aggressive or bizarre behavior

level V confused inappropriate-nonagitated

(a) alert, demonstrate gross attention but have difficulty maintaining selective attention

(b) demonstrate severe impairment of memory functions

(c) responses are fragmented and frequently inappropriate to the situation, reflecting confusion and lack of goal-direction

(d) demonstrate agitation in response to external stimuli

(e) wander from treatment areas

(f) absent carryover for purposes of learning; require an assistance and maximally supervised in activities

level VI confused- appropriate

(a) inconsistently oriented to time and place; recent memory is impaired with decreased detail and depth of recall

(b) follow simple directions consistently; responses are appropriate but may be incorrect if requiring recent memory

(c) supervised for new learning with little or no carryover but show carryover for previously learned skills

(d) actively participate in therapy programs and demonstrate some purposeful behavior but remain dependent on external structure

level VII automatic – appropriate

(a) appropriate and oriented within hospital-home settings

(b) able to go through daily routine with minimal to absent confusion; depth of recall may be shallow, however

(c) demonstrate carryover for new learning although at a decreased rate; require at least minimal supervision for learning and for purposes of safety

level VIII purposeful- appropriate

(a) alert, oriented; intact recall for past and recent events

(b) demonstrate carryover for new learning; function independently , within physical capacities, once new tasks are learned

(c) able to formulate realistic goals for own future; may be candidate for vocational rehabilitation

(d) able to apply adequate judgment to daily living and community situations relative to premorbid ability level

However, all patients do not go through all levels, or all progresses at the same rate. The characterization accompanying each level affords a picture typical of the survivor with brain injury. These levels then are grouped to use as three separate phases of rehabilitation: the stimulation phase, the structure-oriented phase, and the reintegrated phase (Bottcher, 1989). Literature (Baggerly, 1986; Bottcher, 1989; Brillhart & Stewart, 1989; Hall, et al., 1992; DeYoung & Grass, 1987; Grinspun, 1987; Richmond & Craig, 1986; Sosnowski & Ustik, 1994) has demonstrated the formal rehabilitation programs, which are managed by the multidisciplinary team and family involved during the critical and rehabilitation area.

1. **Stimulation phase** includes patients with the Rancho Los Amigos Scale of level I, II, and III. The patients are usually unresponsive to all stimuli, to pain only, or respond to commands and stimuli inconsistently. The goal of this rehabilitation phase is to provide sufficient stimulation. The program is based on theory of neural plasticity to decrease the threshold of the reticular activating system, and increase cortical activity. Families should be involved in the program while they reach emotional, physical and cognitive stability. The nurses will be able to explain patient conditions, identify deficit related to brain injury and progression of recovery, and describe common problems that the patients and their family may experience.

The programs are implemented as soon as the patients are medically stable and intracranial pressure is under control. It begins with the subcortically integrated sense of touch, movement, and olfaction, then progresses to more cortically oriented systems such as the visual and auditory senses (cited by Hall, et al., 1992). The stimulation is performed at least two to three times daily. Since the patient's ability to maintain an alert state is limited, the treatment sessions should be limited to 15 to 30 minutes. The stimuli should be presented in an organized manner to one sensory system at a time. As the responsiveness of the patient increases, efforts are made to increase the frequency, variety and length of time that the patient is able to maintain this response.

Tactile stimuli can be accomplished during bathing and treatment activities. Bathing can provide a variety of stimuli for the patient. The texture of the washcloth, water temperature, the slip of soap and shampoo are stimulants as there are as the sensation of washing ranging from light touching to brisk rubbing. Even when oral feeding is not yet possible but brushing the teeth and applying flavored mouth swabs offer potential input through taste. Moreover, passive range of motion exercise will maintain joint movement. The patient can be moved from side to side in rolling motions. The head of the bed should be raised and lowered and, if permitted, use of the Trendelenburg and reverse positions may be useful.

Visual and audio stimuli are provided by exposure to television and radio, a colorful environment, family photographs, and mobilizing the patient using a wheelchair. Information about likes and interests of the patient such as familiar voices or favorite musical tapes can help to enhance the meaning of auditory input. Olfactory stimuli are provided by placing nonoffensive smells, particularly those which might be associated with the patient's pleasant memories such as the aroma of coffee, milk, or vanilla under the patient's nose.

2. **Structure-oriented phase** includes patients with the Rancho Los Amigos Scale levels IV, V, and VI. These patients display the following behaviors: disorientation, short attention span, impaired ability to process information, and bizarre and inappropriate behaviors. The higher cognitive function of this phase shows the patient appearing more alert, responding to simple commands, and being able to perform mastered tasks. The patients may respond with inappropriate behaviors when they are pushed to learn new tasks. The goals of the structure-oriented phase are to control the patient's agitation and continue family's education and involvement.

The major intervention for controlling patient agitation is to control the environment. These include subdued lighting, a quiet environment, limited contact with others, consistent approach by professionals, and safe provision for the patient. Education for patient is minimal at this stage because of his agitation, confusion, and short attention span. The focus of the education process for family members includes the goals and purposes of environmental control and an understanding of agitated behaviors.

Some periods of agitation may be associated with physical needs or feelings of discomfort, such as a full bladder or bowel the patient is unable to identify and articulate. Assessing these possibilities and planning care to eliminate such events are vital components of the caregiver's role, therefore.

3. Reintegrated phase includes patients with the Rancho Los Amigos Scale of stages VII through VIII. The goals for the patients in this phase concern re-teaching daily living skills, teaching compensatory techniques for functional losses, and slowly reasserting patient self-control and decision making. On the family part, educational goals include stressing the dependent-independent family responsibilities with the patient, a balance of expectations for patient behavior, and modifications of home environment anticipating discharge.

Patient education should take place in a controlled environment with limited distractions. In that interest, limitation of the number of people in the room, elimination of radio or television programs during educational sessions, and working with the patient on a one-to-one basis are required. Educational sessions are conducted in a consistent manner using step-by-step instruction. Ample time is scheduled for educational sessions because the patient's reaction time is generally slow. Lessons should be presented in a consistent pattern and repeated until the patient is able to achieve mastery. If the patient becomes frustrated or agitated, the educator should redirect him or her to a new activity. Moreover, lessons should be limited to the individual's tolerance. A memory notebook is also an excellent tool to assist the patient with memory, self-scheduling, and self-care lessons.

Inappropriate behaviors, such as hitting, kicking, swearing, spitting, or scratching often are an expression of poor tolerance, stress, and frustration. To approach these behaviors, the caregiver should accept the patient's feelings, remain calm and composed, and set limits for their behavior. Time out or quiet times may lower the frustration level for the patient during the times of stress and confusion.

Appropriate self-care responsibilities include bathing, dressing in appropriate clothing, using appropriate table manners, and knowing the rationale for and requesting medication. Activities related to the home also can be practiced within the home setting. The patient should be responsible for making his or her own bed; maintaining his belongings on the unit; planning, preparing, and cleaning up after a light meal; locating personal and emergency numbers in the phone book; making telephone calls; and verbally solving daily problems and home emergency situations. Activities related to the community setting include making changes, purchasing items in the hospital gift shop, participating in community outings, crossing the street, and using public transportation safely.

In summary, the needs of rapid, accurate diagnosis, and appropriate treatment are vital for immediate care after brain injury. A formally rehabilitative program is necessary to facilitate optimal physical and functional return of the brain injured patients. However, the formally rehabilitative program for the hospitalization in Thailand is not taken into serious consideration.

Needs of family caregivers immediately at and after hospital discharge plan

1. Needs of family members at the immediate post injury period

Mauss-Clum and Ryan (1981) described needs during the immediate acute period of 30 subjects comprised 19 wives and 11 mothers of brain injured veterans. The need assessment was conducted at the sixth month after the injury. The samples were asked to describe their experiences at the immediate phase after the patients sustained brain injuries. They were also asked to prioritize a list of professional help that they felt was needed during that period of time and to indicate what help was actually obtained from care providers.

The needs consecutively reported included a kind and clear explanation of the patient condition, a discussion of realistic expectations, an emotional support, a financial counseling, and a resource counseling. Fifty-seven percent of the sample reported that they received a kind and clear explanation, 23% was able to discuss realistic expectations, 50% received emotional support, 10% received financial counseling, and only 3% participated in resource counseling. Twenty percent of the sample indicated that they received no help with regard to the needs as presented above. The finding also showned that 50% of the sample believed that relatives or friends were the most helpful persons, 43% stated that physicians were the most helpful person, while only 17% reported that nurses were the most helpful person at the immediate phase after the injuries had occurred.

The needs of family members of patients with acute brain injury are expected to differ from those of family members of the patients without acute brain injury. Mathis (1984) conducted a comparative descriptive study by interviewing 26 family members of critically ill patients with and without acute brain injury. The study revealed that there was the difference in perceived degree of importance for the need statements between these two groups. While family members of critically ill patients without acute brain injury identified “a hope for patient recovery” as the first priority need, family members of brain injured patients identified “an attention from health care personnel on patients” as the first priority need. Mathis proposed that the different perceptions and needs between these family groups were due to the characteristics of patients’ illness. Patients with acute brain injury required longer stay in intensive care units and appeared to be more dependent than patients without brain injury.

Engli and Kirsivali-Farmer’s (1993) extended Mathis’s finding to compare the needs of family members of critically ill patients with and without acute brain injury. Data were gathered using a quantitative questionnaire. The study disclosed that statistically significant differences were found between the 2 groups, supporting Mathis’s finding. In the analysis of data concerning whether needs were met and by whom, family members of critically ill patients identified the need for more information concerning the condition, prognosis and treatment of the patient as the priority. They considered the doctor as the person who most frequently provided them with what they needed.

Unlike family members of critical ill patients who are conscious, making decisions can be difficult for family members of patients with brain injury. To determine factors affecting family decisions, Mirr (1991) interviewed 19 family members of patients with severe brain injury. The interviews were conducted on 3 consecutive day—the first interview occurred 24 to 48 hours after patients' admission, and the second and the third interview occurred at the first week and the first month respectively after the patients' admission. It was found that six factors: personal functioning, relationships, information, uncertain outcomes, environment, and emotions were significant factors that influence family members in their decision making process.

Intention of nurses to assist families to meet their needs is not always accomplished, however, nursing research on identification of family needs can assist the nurses to reduce discrepancies between the needs perceived by the nurse and those perceived by family members. Kitiratragarn (1998) explored the needs perceived by 123 family members of critical ill patients with acute brain injury and those perceived by 107 professional nurses working in surgical intensive care unit of six hospitals. The findings showed that the first major need of family members is the need for the relief of anxiety and the last is the need for support and ventilation. The first major need perceived by nurses was the need for the relief of anxiety and the last was the need to be with the patients. The comparison indicated the perceptions of needs among family members are higher than those of nurses. Besides, most family members perceived their needs are met and nurses are identified as meeting their needs most.

2. Needs of family members at the hospital-discharge period

Addressing the needs of caregivers of brain injured patients outside the hospital, Campbell (1988) identified the perceived needs of relatives living with a brain-injured person and participating in a support group for caregivers. In surveying 14 relatives of brain injured individual, Campbell found that the major needs of the relatives were the information related to management techniques when the patients developed behavioral problems. Educational needs focusing on information about the effects of head injuries, community resources, and financial assistance were also identified as a priority need. Psychological needs emphasized the need to feel hopeful, to receive emotional support, to be able to express feelings, and to know the future were identified. The participants also recommended that support groups among family members be very helpful.

Acorn (1993) assessed the needs of 42 caregivers of head injured survivors and the availability, usage and helpfulness of support groups in meeting these needs. The results indicated high educational need focused on information concerning the effects of head injuries, community resource, and questions answered honestly by health professionals. The highest psychological need was to know what the future holds for the survivor whether he or she is able to talk about one's feelings, feels the hope, and has emotional support. Sixteen (38%) respondents did not attend a support group. Fifteen reasoned that support group did not exist in the area, and one indicated previous attendance at a support group but stopped attending as more support was received. Twenty-four attending support groups found them most helpful in three areas: having questions answered honestly, receiving emotional support, and identifying community resources.

Grant and Bean (1992) conducted the study in 84 informal caregivers of brain injured individuals in the home settings. Questionnaire methods were used to collect data. In this study, needs were identified as self-identified intra-personal, interpersonal, or extra-personal stressors that could result in an imbalance in the physiologic, psycho-sociocultural, or spiritual system of the informal caregiver. Informal caregivers identified 110 different needs. Of those needs, 37 were categorized as intra-personal stressors that most frequently experienced as time for self, and time for social activities. Twenty-four needs were categorized as inter-personal stressors that most frequently experienced as the need for support groups. Forty nine needs were related to extra-personal stressors that were most frequently experinced as need for respite care, financial support, day care programs, alternate housing or living arrangements, information about brain injury, individuals to live with or care for the injured survivors, transportation services, information about care of the survivor, and information about facilitating resources.

Family members as family caregivers : a concept of dependent care agency in Orem's General Nursing Theory

The number of people who have been placed in family caregivers role has increased because more elderly, chronic illness and disability requiring assistance from family member are on the rise. A different terminology has been used to refer to the person who cares, such as informal caregiver, family caregiver, or caretaker. Family caregivers are the relatives, friends, or significants other of a care recipient (Davis, 1992). They provide unpaid care to an ill, infirm, or dependent care recipient at home or community. Sirapo-ngam (1996) proposed the defining characteristics of caregivers in 4 aspects: 1) The caregiver who assumes primary responsibility for providing care is parents, spouse, child, relative, friend or other significant person of care recipient; 2) Caregiving is a specific task for an individual who is necessitated by some degree of vulnerability or impairment of physical part, cognition, or emotion; 3) Caregiving is unpaid provision of care; and 4) Caregiving is the care given to recipient mainly in the home or community.

Responsibilities of family caregiver is identified as primary and secondary caregiver. Primary caregiver refers to the person who is able to give direct care to a care recipient most of the time. Secondary caregiver is a temporary caregiver assistant (Selected Committee on Aging, 1988 cited by Sirapo-ngam, 1996). Horowitz (1985 cited by Davis, 1992) described four types of services that family caregivers provide including direct care services, emotional support, mediating with formal organizations, and financial assistance. The family caregivers may provide one or more of these services during a long-term caregiving experience. The family caregivers give care to the recipients doing everything they could, such as giving time and energy in caring for care recipients. Their task draws on feeling of love, obligation and duty (Twigg, 1992 cited by Kirk & Glendinning, 1998). In general, family caregivers are most likely to be female (Acorn, 1993, 1995; Almberg, et al, 1997; Biegel, et al, 1994; Gasemgitvatana, 1996; Oberst, et al, 1989).

Literature suggested that several potential factors influence family caregivers' readiness, competence, and available time to care for a care recipient. Suwanno (1997) found factors influencing family caregivers' capabilities in caring for hospitalized stroke patients before discharge including motivation, knowing the goals for observation and care, skills in establishing the relationship, and seeking support from others. Self-learning and formal-learning from nurses and other care personnel are the two methods the family caregivers acquired. These are knowledge and skills required to care for the patients. The influencing factors include personal, interpersonal and situational factors such as age, gender, marital status, occupation, personal health problems, motivation, financial resource, social support, caregiving experience, and burden in caregiving role (Sirapo-ngam, 1996; Suwanno, 1997).

Family caregiving process is congruent with the concept of dependent care agency in Orem's theory. Dependent care agency is analogous to self-care agency. That is the capability of family caregivers to perform estimative, transitional, and productive operations to know and meet the therapeutic self-care demand of the care recipient. In addition, there are enabling power components specific to the operations as an operation related to knowing and meeting components of the therapeutic self-care demands. Both of these depend on foundational capabilities and dispositions and basic conditioning factors of the caregiver. Dependent care is the action of mature and maturing persons who have developed the capabilities to take care of themselves and their dependents in their environmental situations. They are the practice of deliberate actions that individuals initiate and perform on their own and their dependents to maintain life, health, and well-being (Orem, 1995).

Traumatic brain injury has profound effects on cognition, behavior and physical body of the survivor. These preclude survival capabilities on decision making and practice the deliberate action. As a result, the survivor requires care from others. In the family structure, the members of the family such as parents, children, or spouse who relate to the patient will be a responsible person to care for him or her. For the family caregiver of traumatic brain injured patient, this complex ability must be performed to care simultaneously for the patient and the caregiver himself or herself. The family caregiver acquires knowledge and skills to care for the patient to maintain health and wellness. He or she also needs motivation, time, energy, strong resource support and social facilitation.

Evidence from several studies has demonstrated that being a family caregiver can be very stressful (Hall, et al, 1994, Livingston, et al., 1985a). Caregiver's roles can consume much of the caregivers' privacy and time, personal life, as well as social activities (Grant & Bean, 1992; Livingston, et al., 1985b). The effect of impairment on caregivers' stress is stronger for personality and behavioral change than it is for limitations in intellectual or physical change (Mauss-Clum & Ryan, 1981). Moreover, spouse caregivers have larger number of complaints than parents' (Hall, et al., 1994; Mauss-Clum & Ryan, 1981). The situations affect family caregivers' capabilities on self-care and dependent-care. These can be expressed in term of dependent-care deficit, or the family caregivers' need of supports.

Nurses have often assumed that self-care involves empowering both the patient and family caregivers, but they have neglected to consider the fact that most health care is delivered in a system guided by the medical model. The deliberate action is difficult to handle in health care settings where they are dominated by the medical model. Nurses are not successful in empowering the family caregivers when the physicians and nurses control decision making and actions.

Traditional approach to the brain injured patients and their families

1. Traditional approach to the brain injured patients

Due to medical advances and improved trauma care, more patients with traumatic brain injury survive than they previously did. Survival itself is no longer the crucial issue. Currently, the key issues are the quality of survival and the successful rehabilitation of the patient. Several rehabilitation programs have been proposed to enable the brain injured patients to maximize their ability in both critical and rehabilitation area (Baggerly, 1986; Bottcher, 1989; Brillhart & Stewaet, 1989; Hall, et al., 1992; DeYoung & Grass, 1987; Grinspun, 1987; Perry, 1983; Richmond & Craig, 1986; Sosnowski & Ustik, 1994). The effects of rehabilitation program were reported in a controlled study by Kater (1989), and Mackey and colleagues (1992), which indicated that the formalized rehabilitation programs reduce coma duration and length of hospital stay.

Clinically, it has long been believed that active, timely, and appropriate rehabilitation programs lead to improve functional recovery of the brain injured patients. However, more experimental support for this belief has been gained from animal studies. Yu (1976) reviewed information on recovery with and without training in experimentally lesion animals. He concluded that training leads to improve functional recovery. The exact basis for the recovery observation is unknown, but it may be explained by the vicariation and substitution theory of brain recovery.

The vicariation theory maintains that following brain injury, the function will be taken up by uninjured areas on the same side of the brain. A possible explanation underlying the vicariation theory is the occurrence of anatomical and physiological changes, such as axonal sprouting, rerouting, and anomalous connections to a different area of the brain. The result of functional recovery is based on neuronal substrate changes in another area of the brain. According to the substitution theory, the subject is relying on compensation mechanisms that are characterized by substituting one type of system for another (Ansell, 1991; Backer, 1988; cited in Kater, 1989).

Based on the vicariation and substitution theories, many studies extended testing of the model from animals to humans. Regarding human studies, LeWinn and Dimancescu (1978) reported a pilot study which used enrich environmental program to expedite recovery from coma. The program was performed in 16 consecutive severe coma patients. The first neurological examinations were done within 6 hours of the onset of coma and was repeated daily. Enrich environmental programs were started from 12 hours to 24 hours after admission to hospital, except in the two postoperative brain tumor patients whose program started 10 and 14 days after surgery, and follow-up ranged from several days to 10 months. The study revealed that all 16 patients fully recovered from coma. On the other hand, a comparable group of 14 consecutive severe coma patients received no program and eleven of them died. Although enrich environmental programs are recognized as advantageous to brain injured patients, the techniques are usually reserved for patients in rehabilitation settings. Literature suggested early designed programs as medically possible for patient's stability after injury could improve the patient's functional outcome and ultimately quality of life (Sosnowski & Ustik, 1994).

A study focusing on benefit of early rehabilitative intervention was completed by Cope and Hall (1982). They examined the effect of time entering into intensive rehabilitation programs on survivors' final outcomes. The study used a median split, which was 35 days post trauma, to separate patients to early and late admissions into rehabilitation. These groups were matched for coma duration less than 15 days, age, gender, computed tomography (CT) scan abnormalities, incidence of surgery and medical or surgical complications, and level of initial disability. The study demonstrated no difference in outcome at two years post injury as a result of early or late admission to intensive rehabilitation. However, early admission resulted in fewer days in the rehabilitation program. This study supported the clinical assumption that rehabilitation is most efficient when it is early and intense.

Morgan and colleagues (1988 cited by Mackay, et al., 1992) measured the progress of 82 out of 128 patients who were treated during their acute hospitalization. The results indicated that earlier trauma rehabilitation (≤ 7 days post injury) was associated with better outcomes in the areas of cognition, perception, and motor skills at the time of their discharge from the hospital. Those patients displayed marked improvement after a hospital stay averaging 24 days, compared to an average length of stay (LOS) of 45 days for patients with rehabilitation intervention beginning ≥ 8 days post-injury. The patients admitted in coma with the average LOS improved from 75 days to 31 days with trauma rehabilitation.

In an experimental design study by Kater (1989), cognition was measured at 3 months post injury for two groups of head injured patients. The groups were matched for sex, age range, approximate type of injury, Glasgow Coma Scale Score, and length of post injury time. The experimental group received structured sensory stimulation but the control group did not. The stimulation was directed through various sensory modalities including visual, auditory, olfactory, gustatory, cutaneous, and kinesthetic. Significantly higher cognitive scores were found for those patients who received sensory stimulation programs and also for patients who came from enriched environments prior to their injury.

Using the controlled study, Mackay and colleagues (1992) reported their findings correlated closely with those of Kater. In their research, 17 comatose patients obtained acute care at a hospital with a formalized early intervention traumatic brain injury program. The comparable group comprised 21 comatose patients receiving acute care service at ten different hospitals without formalized brain injury programs. The results revealed that the experimental group had approximately one third less coma duration and rehabilitation stays than the control group. Greater gains were also made in cognitive and physical areas for the patients involved in early formalized trauma rehabilitation.

Sisson (1990) examined the patient's responses to auditory stimulation. Five participants comprised three young male adult patients and two young female adult patients with brain injury were provided with the specific auditory stimulus, a recording of two currently popular songs. The findings indicated that participants responded to auditory stimulation. Either behavioral or an alerting response on EEG appeared to indicate the variety of responses.

Jones and others (1994) measured the effect of auditory stimulation on a comatose traumatic brain injured patients using four types of tape-recorded material to serve as the auditory stimuli including family and friends talking individually to the participant, classical music, rock 'n roll music, and nature sounds. The study demonstrated greater increases in responsiveness with the presentation of taped voices of family and friends than with other types of taped stimuli.

The results of these studies support the idea that patients with strong family support progress more than the patients without family involvement. As previously reported, the researcher placed an emphasis on the treatment, which were the controlled study and manipulated by the researcher with the knowledge that professional knew best, and families played the passive role. The findings were unclear that family involvement in care was active participation. There is no evidence to support whether family caregivers taking part in care's need was met, and that they were satisfied with the role they played in patient care.

The early rehabilitation to promote patient recovery in Thailand is limited. Only one study conducted by a nurse, Intorn's study (1996), reported the comparison effects of two groups of head injured patients with and without relatives' involvement. Although the results showed that the group of patients with relatives' involvement were less complicated than those without the involvement, but it showed no statistically significant differences on functional recovery, length of hospital stay, and relative satisfaction with care between the study and the control groups. The degree of family caregivers' participation in caring was one issue the researcher considered within this context. The obvious factors influencing the degree of participation are the socioeconomic factors and organization structure (Arnantapunpong, 1995; Suwanno, 1997). These factors are important to facilitate their choice to participate in the project. The staff's attitude and ward's policy are also the key factors to encourage family caregivers to participate in patients care (Sharp, 1990).

2. Traditional approach to families of traumatic brain injured patients

Literature described the problems and the needs to develop coping skills and to manage stress of the families. The authors suggested several approaches as part of strategies to reduce stress of families of traumatic brain injured patients during hospitalization and home care.

Elliott and Smith (1985) demonstrated the strategy to diminish family stress in the acute care setting at Hermann Hospital. A multidisciplinary approach was utilized to meet the family's needs following severe brain injury. The authors illustrated that meeting the family's needs required assessment of each family's needs, communication among the health care team, and genuine concern. They also claimed that family huddle was a one successful technique to the group process at this institution.

Rogers & Kreutzer (1984) described the social network intervention to help the family develop a support system. Several sessions were applied including discussion family needs, provision of appropriate information to families, a brainstorming anticipation of potential problems and solution generation, and goal formulation. The approach was found to help reduce an emotional and related stresses caused by a brain injury.

Johnson & Roberts (1996) proposed hopeful nursing strategies, organized to help the family reduce hopelessness and achieve a sense of hope. The strategies consist of informational strategies, decision control strategies, environmental structuring strategies, interpersonal relationship strategies, proximity environment strategy and emotional support strategies. Fowler (1995) stated that facilitating hope in the health care setting results from an understanding of its definition and significance to nursing, multidisciplinary origins and scientific investigations. Nursing interventions should include modification of an environment, identification of goals, establishment of relationships with patient and family, change of situations, and facilitating energy for hope.

Families experience stress resulting from the effects of brain injury at any time during hospitalization. Literature suggested that the time to transfer the patient from an intensive care unit to a general care unit is crucial. Addressing effective family conference to reduce family anxiety at this time, Bokinskie (1992) conducted a quasi-experimental study using a pretest-protest design. The twenty-two family members were randomly assigned to the control group and the experienmental group. The subjects were given the State-Trait Anxiety Inventory (STAI) within 24 hours prior to transfer of the patient from the intensive care unit, and within 24 hours after admission to the general care unit. The experimental group received a care conference after having completed the first test and prior to transfer of the patient from the intensive care unit, while the control group did not receive this conference. It was found that the group received the care conferences reduced anxiety they experienced when the patient was tranfered from the intensive care unit to a general care or rehabilitation unit.

Campbell (1988) assessed the perceived needs of relatives living with brain injured survivors and the help of the family support group in meeting their needs. Questionnaires were distributed at five separate support meetings with fourteen subjects participating in the study. The results revealed that the family support group was identified as being helpful in meeting some of the educational and psychological needs; however, social needs were perceived as being met less frequently.

Acorn studied (1993) 24 caregivers of brain injured survivors and showed that support groups were most helpful in meeting educational and psychological needs of caregivers. The support program provided the caregivers with information and support which would assist them to better understand and care for a brain injured survivor at home. The detail of the program was well documented (Acorn, 1995).

There are few studies with related reported on strategies to approach families of Thai brain injured survivors. In considering existing strategies to approach families of disabled and elderly people, family education seems to be a major concerning issue among health care providers since it has been routinely offered to families as one of the regular nursing practice in health care setting. According to nursing research with the focus on effectiveness of nursing interventional programs, family education has become the most popular strategy of all. Although providing families with education can improve their caring abilities and increase their effectiveness in caring for the clients (Srepatarapinyo, 1997) the families who receive only formal education require associated factors during hospitalization to promote health and compliance in patient care (Arnantapunpong, 1995; Intorn, 1996; Suwanno, 1997).

Alternative care

As previously stated, the existing care is considered to be inadequate to enhance the health of traumatic brain injured patients, families' ability, and their compliance in patient care during hospitalization. Alternative care, therefore, is discussed: (1) family participation in patient care, and (2) participatory action research.

1. Family participation in the hospitalized care

Family participation in patient care is considered to be particularly important for seriously ill, severely disabled and elderly people. However, there is very little document addressing family participation in the hospital setting, although family members do continue to provide various types of services to their hospitalized relatives. The practice range from giving physical care to performing complex care activities.

Brownlea (1987) stated that participation means getting involved or being allowed to involve in a decision-making process, taking part in care, an evaluation of care, or even simply becoming one of a number of consulted people on an issue or matter. World Health Organization (WHO, 1979) recommended that participation in care is a right and a responsibility of patients and/or family to be involved in their health care. Consistent with the patient's right proclamation (1998), the patients or their proxy is an individual with the right to appropriate skilled health services to meet their need, and to have real freedom of choice in their care. They have the right to knowledge and understanding of their condition and problems to enable their to make rational decisions.

A number of benefits have been claimed for families' involvement in patient care. These include improving family compliance, diminishing dissatisfaction, increasing efficacy of health education and consequently decreasing health care cost of the participation.

Most of the literature described that many relatives seek increase their participation in patient care, but they are prevented from doing so by the obstructive attitude of nurses (Laitinen, 1992; Laitinen & Isola, 1996). Traditional attitudes and routine practices continue to prevent progress towards equality in decision-making and sharing of expertise between relatives and nurses (Casey, 1995). On the other hand, some studies indicated that the majority of nursing staff wish to have relatives involve, though the relatives express satisfaction with the minimal role in patient care (Sharp, 1990). The studies by Laitinen (1992, 1993) on family participation in hospital care were specifically concerned with the involvement of relatives of elderly patients and with an evaluation of the quality of care. The results showed that there was little active involvement on the part of relatives in the patient's daily routines.

Specific factors promoting and inhibiting the participation have been identified by Laitinen and Isola (1996). They implied that if the caregivers are in a good state of health, they are active and interested, have enough time and receive emotional and cognitive support from nursing staff, then participation in hospital care would be successful. Many authors emphasized that lack of communication is a main factor in limiting family participation in care (Casey, 1995; Laitinen & Isola, 1996). Sharp (1990) pointed out that the severity and type of illness the patient is experiencing results in relatives' withdrawal from involvement. Several other factors related to environment were also mentioned. Bureaucracy, lack of privacy and fixed visiting time can prevent relatives from participating in patient care (Laitinen & Isola, 1996). Other characteristics, such as cultural background, age, gender, diagnosis, previous health care experience and educational background of individuals, are also likely to influence the desire to be an active participant in care (Astedt-Kurki, et al., 1997; Trnobranski, 1994).

Participation in care necessarily involves the changes in relationships between nursing staff and family caregivers. This means the shift of attitude and style of nurses from the compliance approach to one of empowerment and partnership. Relationships based on partnership would be characterized by negotiation role with both parties recognizing and valuing one another's contribution and knowledge, by joint care planning, and by collaboration in both goal setting and in the evaluation of care (Ashworth et al, 1992; Brearley, 1990).

Those caregivers who do wish to participate in patient care are important since the environmental factors can facilitate their choice. However, it remains difficult for the family caregivers to know what role to adopt or where they may fit in. Sharp (1990) proposed some practical aspects which may help to overcome the problem. This included (1) development of ward policies designed to encourage greater involvement of relatives; (2) production of booklets or information leaflets to be handed out to relatives on admission and transfer to long-stay wards, which outline these policies; and (3) increasing communication between relatives and nursing staff by spending time to talk and interact with each other.

2. Participatory Action Research (PAR)

Participatory action research (PAR) is a way of doing research and working to understand and improve the situation (Street, 1997; Webb, 1991). It is a form of collective self–reflective enquiry undertaken by participants in social situations in order to improve the rationality and justice of their own social practices, as well as their understanding of these practices and the situations in which these practices are carried out (Kemmis & McTaggart, 1990). Participatory action research is a valuable research method for nurses interested in examining those areas of concern to them in their day-to-day practice and working with their colleagues to change things in order to improve the quality of care (Chuaprapaisilp, 1998; Stress, 1997). It is designed specifically for bridging the gap among theories, research, and practice and incorporate both humanistic and naturalistic sceintific methods (Holter & Schwartz-Barcott, 1993).

Participatory action research is one method of carrying out critical science. It aims to produce knowledge and directly useful action to a group of people, and to empower people especially less powerful people, or the oppressed group. The research therefore transforms the subject-object relationship to a subject-subject one (Holter & Schwartz-Barcott, 1993; Neuman, 1997; Reason, 1994; Small, 1995).

The most significant feature of participatory action research is the participation of researcher and study participants in the research process. The participants are primarily responsible for the design of the study, deciding how the data will be collected, analyzed, and eventually disseminated. The researcher plays the role of the facilitator of the process, an important role in the selection of methods by presenting the various options along with their strengths and weaknesses. The researcher may also help participants to consider the human and financial resources available, and contribute by sharing the research expertise and educating participants about how to implement particular methods. A vital aspect of participatory action research is its use of a variety of methods including both quantitative and qualitative approaches.

Participatory action research is typically described as a cyclical process involving a number of stages including collecting data on action, diagnosing a problem, developing a plan of action, implementing the action plan, data collection, analysis and critical reflection, and revised plan and re-implementation (Chuaprapaisilp, 1998; McTaggart, 1991; Stress, 1997) (see Figure 1). These can be either worked simultaneously or orderly throughout the process until participants' appropriation and satisfaction of the model are gained.

Participatory action research has been used in nursing in a variety of ways. To enhance nursing autonomy, Breda and colleague (1997) used participatory action research as a tool to explore issues of nursing autonomy at a small rural psychiatric hospital. The investigator conducted the weekly meeting of nurses for study and discussion. The study group allowed the participants to learn from each other, to share their experiences, and to produce useful knowledge to them. The result demonstrated that they were able to successfully challenge the institutional norms and ideas that limit nurses' autonomy.

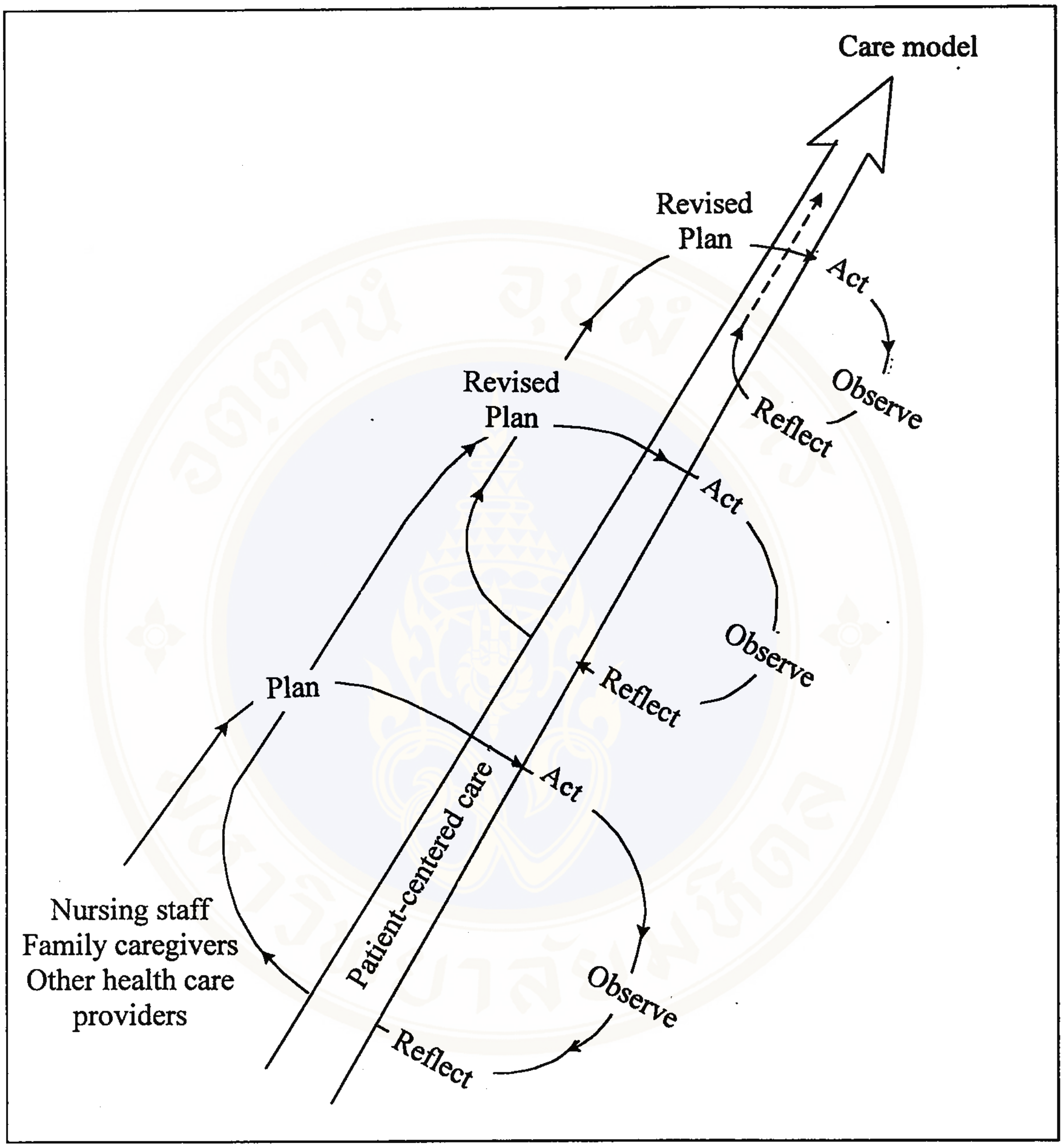


Figure 1: The Participatory Action Research Process

(Modified from Chuaprapaisilp, A. (1999). p. 3)

Keeratiyutawong (1994) utilized participatory action research to develop a model for promoting self-care among diabetic patients to control the level of glycosylate hemoglobin (HbA1c), and to increase perceived self-care agency and patients' satisfaction with care. Thirty adults with non-insulin dependent diabetes mellitus in the outpatient diabetic clinic, Chachoengsao Hospital, participated in the study. The investigator promoted patients' self-care agency both by individual and group meetings once a month for four months. The level of glycosylate hemoglobin (HbA1c), perceived self-care agency and satisfaction with care had been measured before the patients entered the program, and four months later. Qualitative data pertained to factors influencing self-care behaviors, process of self-care agency development and method of promoting self-care agency were obtained using the depth interviews, group discussions and participant observation.

The results indicated that the patients' level of HbA1c decreased significantly, whereas perceived self-care ability and satisfaction with care increased significantly after participating in a self-care promotion program for four months compared to those before entering into the program. Qualitative data pertained to factors influencing self-care behavior could be categorized into internal and external factors. An educative-supportive nursing system was used to promote self-care agency with eleven methods of helpings. The aims were to empower the patients to be the agent of their own care.

Similarly, Wattana (1997) applied participatory action research to develop a model for participatory caring relationships between nurses and patients to enhance self-care abilities of patients. A purposive sample of 16 nurses and 20 adult patients in Kanghangmaew Hospital participated in the study. The researcher and the nurses reflected on the quality of care, and a strategic plan was established to improve the quality of nursing practice which aimed to allow patients' participation in self-care focusing on the caring relationship.

The finding showed that a model of one-to-one nurse-patient continuity of caring relationship was developed to enhance patients' participation in self-care. It consisted of four phases: initiating impressive care relationship, continuity care collaboration in solving health problems, preparation for home self-care, and modifying home self-care. Seven strategies were used to improve nurse caring attitudes and behaviors: reflecting on quality of care, mutaul agreement in improving the nursing care practice, providing information and knowledge, role modeling, empowering for nursing care management, support among colleagues, and reflecting on positive outcome of care. The patients' participation in care included being openly given information, mutually setting goals with nurses, negotiating medical treatment and nursing care, being responsible for daily self-care activities, evaluating self-care management, planning for home self-care, prevention of recurrence of illness, and promoting health. The patients also perceived seven self-care abilities. Both nurses and patients were highly satisfied and appreciated engaging in the participatory caring relationship model. However nurses perceived three major obstacles—heavy work load of non-nursing work, patients' difficulty in learning and patients' economic problem.

Using action research, Hanucharurnkul and other (1995) developed the model to assist the patients in coping with cancer. A purposive sample of 20 patients with leukemia and lymphoma in Ramathibodi Hospital participated in the study. The researchers established relationships, provided education, and gave continued attention and to the patients assistance 5-7 times a week. The score of morale, influencing factors, and discomfort had been measured at three times, when the patients entered the hospital, during receiving chemotherapy, and before discharged from the hospital. The results revealed that the mean scores of their morale increased significantly, whereas the discomfort decreased significantly during receiving chemotherapy, and before discharged from the hospital compared to entering into the hospital. The model for assisting the patients to increase the morale was the compensatory model consisting of eleven methods of help to empower the sample to be the agent of their own care.

Nantachaipan (1996) utilized action research to develop the model of promoting self-care in persons with HIV infection/ AIDS. Sixty persons with HIV infection/ AIDS participated in the study. The investigator provided clinical services and home visits 1-6 times a month for 3-6 months consecutively. The research process relied on mutual collaboration between the researcher and participants in sharing information; determining self-care demand, self-care ability, and self-care deficit; defining the problems and related factors; and exploring and selecting means to manage those factors in order to promote the individual's self-care ability. The model of community-based home care services with case management was used.

Based on the qualitative data, six domains of nursing role: management of physical mental illness; monitoring and ensuring the quality of health care practices; management of changing situations; organizing self-care system; promoting patients to learn how to live with AIDS; and collaboration with other significant persons were found. Methods of help to meet those nursing domains could be categorized as establishing a therapeutic relationship; counselling; assisting in defining situations/

problems; teaching about caring; giving information; using modern and traditional approaches to cure and care; providing options and rights in decision making; promoting skills in critical thinking; providing direct care; refering to appropriate resources; and cooperating with family and other persons. Several methods were used simultaneously for each person based on the conditioning factors. Additionally, the results indicated that after participation in this study program, the persons with HIV infection/AIDS improved ability in self-care practice with fewer symptoms, and had better quality of life than before entering into the program.

Hirunchunha (1998) used action research to develop a care model for caregivers of stroke patients at home. The research process was based on a mutual collaboration approach among the researcher, 15 primary caregivers and their families, and the health team. The findings revealed that the suitable care model for caregivers of stroke patients at home consist of caregivers transformation process, promoting care at home, care-related factors, caregivers' caring competencies, and caring outcome. Caregivers' transformation process is comprised of four stages: inability to adjust/think, a transition period, seeking/modifying caring techniques, and settling into a normal lifestyle. Promoting care consists of preparing caregivers, developing caregivers' caring and self-management abilities, developing self-reliance on their caring abilities and adjusting to their role, and maintaining quality of care and adjusting their lifestyle. Moreover, the strategies in promoting care include building trust and confidence, promoting self-reflective skills, mutual participation, seeking support groups, empowerment, incorporating traditional and non-traditional caring beliefs, reinforcing caregivers' abilities, providing mutual encouragement, establishing spiritual support, and being friends. Finally, care-related factors consist of caring experiences, family participation, hope, family support, caregivers' health status, levels of self-care demands, social support, creativities of caregivers, and economic status.

The study identified specific nurses' roles in promoting caregivers' caring competencies in providing independent care for stroke patients at home. The model also ensures the patients' safety without complications. Furthermore, some caregivers are able to resume their previous lifestyles when the patients are able to take care of themselves.

These studies have demonstrated that the action research is an appropriate approach to increase self-care abilities and patients' satisfaction with care and to promote caregivers' caring competencies. The approach raises understanding of the development process, influencing factors, appropriate method provision, and limitations. Evidently, it gives power to research participants by allowing them to construct and use their own knowledge and experience and to produce knowledge and useful action that allow them to implement sustained changes in their existing system for themselves. Besides, participatory action research can help to bridge the gap between theories research and practice in a clinical setting. This approach will be suitable to develop a model for family caregivers' participation to enhance dependent care abilities which will ultimately contribute to recovery among patients with traumatic brain injury.

Summary of literature review

Traumatic brain injury impacts on both survivors and families. The patients experience prolonged dependency with personality changes, inappropriate social behaviors, and physical impairment, while the family encounters financial problems, the change of familial roles, and an uncertain future. Moreover, family caregivers frequently report overwhelming depression, which can persist for years following the initial injury. However, the support system, long–term rehabilitation and community resources available for family caregivers during hospitalization and after hospital discharge are scarce. The family's ability to facilitate patient recovery and manage ongoing special care needs is critical to the outcome.

Promoting patient recovery through family involvement has received increasing attention from the health care providers. Although many studies showed that strong family support has improved recovery of the patients, in the previously mentioned studies it is still unclear whether family was an active participation. There was no evidence to support whether family caregivers who had taken part in care had their needs met, and whether they were satisfied with the role they played in patient care.

A concept of family participation is considered to be most useful in enabling families to regain control and their autonomy to achieve their needs and health. Many authors have pointed out obvious factors influencing the involvement: they are attitudes and style of nurses, and environmental factors which induced an obstacle to implement the idea of family participation. Participation in care necessarity involves increasing understanding of this important issue, the changes in relationships between nursing staff and family caregivers with a shift in the attitude and style of nurses from a compliance approach to one of empowerment and partnership, and facilitating the environmental factors. Greater understanding of both the concept and practice can lead to effective interventions to encourage and support family caregiver is participation. Also, a flexible approach to planning and implementing participation in care is required.

Several studies demonstrated that participatory action research is a suitable research approach which contributes to the development of the model of patients and family participation in health care. The empowering and collaborative nature of the research could contribute to the increase in the patient's and family's care abilities, satisfaction with care, and promotion of optimum recovery for the clients. Currently, family participation in health care in a hospital setting is limited in terms of clinical practice, especially among severely disabled survivors. The care model development for family participation in caring of traumatic brain injured patients therefore is crucially needed in Thai soceity.

CHAPTER III

METHODOLOGY

This chapter presents the research design and methods which are organized into the following topics: first, the research design, study participants, and research setting are described; second, research instruments and the process of data collection are illustrated; and finally, data analysis is explained.

Research design

The design of this study is participatory action research. The approach relies on a collaborative process between family caregivers and nursing staff to develop a model for family caregivers' participation in caring for traumatic brain injured patients. It took twelve months (April 2000 to March 2001) to carry out the program.

Participants

The study included nursing staff and family caregivers of traumatic brain injured patients receiving treatment at the Neurosurgical Ward, the 6th floor of Kum Klao Building, Bhumibol Adulyadej Hospital, Directorate of Medical Services of the Royal Thai Air Force.

1. Nursing staff:

Participants consisted of 30 nursing staff with one head nurse, 12 registered nurses, 5 technical nurses, and 12 nurse aids.

2. Family caregivers:

Families were initially approached at the time the traumatic brain injured patient were admitted to the Neurosurgical Ward. Prospective family caregivers were family members, relatives or any other significant persons of the patients sustaining traumatic brain injury. They provided unpaid care during hospitalization and continuity of care at home.

The eligibility criteria for inclusion in the study were:

1. the primary caregivers who were able to spend most of their time on direct care of the patients; and
2. the persons with 15 years of age or older who agreed to participate in the study.

The survivors of traumatic brain injury must meet the following criteria:

1. be at least 13 years of age with no upper age limit restrictions,
2. show a Glasgow Coma Scale at least 6 scores, and Ranchos Los Amigos Scale level II and over when entering into the study.

The exclusion criteria were either the patient's death or early transfer.

Maximum variety sampling (Morse, 1994) was utilized to describe high quality case and identify significant shared patterns of commonalities existing across participants. With this technique, participants from a variety of backgrouds including age, gender, marital status and socio-economic status of the patients and family caregivers were deliberately selected.

Twenty-five family caregivers agreed to participate in the study. After being enrolled into the study, 3 family caregivers were not able to participate throughout the program, one was dropped from the study due to her relative survivor being transferred to a private ward, and two were dropped out owing to the dead of the patients. The final number of participating family caregivers was 22, consisting of 18 primary caregivers of one caregiver per one patient, and 4 major caregivers of two caregivers per one patient.

Research setting

The study was implemented in the Neurosurgical Ward, the 6th floor of Kum Klao Building, Bhumibol Adulyadej Hospital, a teaching tertiary care hospital of the Royal Thai Air Force. It is located in the center of traffic communication and community industry. Many traumatic injured patients are seen around this area, especially traumatic brain injured survivors. More than half of moderate and severe traumatic brain injury with Glasgow Coma Scale scores less than 13 are found. These cases require complex, long, and continuity of care.

The Neurosurgical Unit is composed of 6 intensive care beds and 24 acute care beds. The acute care service with high technology is provided by 31 nursing staff, one head nurse, 12 registered nurses, 5 technical nurses, 12 nurse aids, and one office attendant. During the day-shift, 11 nursing personnel consist of one head nurse, 4-5 registered nurses, 1-2 technical nurses, 3 nurse aids, and one office attendant were responsible for provision of patient care. On weekends, holiday day-shifts, and evening and night-shifts, two registered nurses, one technical nurse, and 3 nurse aids were responsible for provision of patient care.

Information gained in participants observation revealed that nursing staff provide patient care through team models, functional models, and helping each other. Since a large number of critically brain injured patients require complex, hasty and continuity of care, the main provision of care involve physical care, and management of the physician's treatment plans. Most of the relatives obtain information from nurses emphasizing hospital policy, hospital setting, cost of inpatient care, and what the family was allowed to perform in the hospital, whereas a few of them obtain general information from nurse aids. The majority of nursing staff are uncertain about the patients' conditions and progression. Nursing procedures are emphatically described about 'what to do' and 'how to do', but they rarely explain 'why these procedures have to be done.' Most medical procedures are explained to the patients' relatives, and are performed without family participation in decision making. Besides, the mainly provided routine cares, numerous collaborative projects of Nursing Services Department such as Nursing Team, Health Education, Infectious Control, Ha Sor (cleaning) Project, many activities to prepare for Hospital Accreditation Project, and non-nursing work such as paper-work are assigned to each nursing staff member at the ward. They are seen as an additional work or responsibility sideline overload.

Normally, visiting hours are from 11.00 a.m. to 08.00 p.m. A family caregiver is permitted to provide patient care with one family caregiver per one patient from 11.00 a.m. to 07.00 a.m. of the following day, and no visitor is allowed from 07.00 a.m. to 11.00 a.m., because this period is spent for physicians' round, and nursing provision. The family caregivers' tasks involve in the patients' daily living activities such as bathing, grooming, feeding; preventing other complications by changing the patient's position and range of motion; and supervision and surveillance in order to avoid dangerous accidents.

Because of a large number of nursing duties and an unclear family participation concept, the family caregivers training program is informally learned and only occasionally arranged. The nurses who play the trainer role do not concern themselves with either assessing family caregiver's readiness or choosing the appropriate way to enhance their competency. Most teaching method and information are used for clinical learning and skilled training. Detailed information on how family can be more closely involved is not mentioned. In addition, they also lack supervision and evaluation about the continuity of care. Traditional attitudes and routine clinical practice induce the obstacle to enhance family involvement. Consequently, nursing staff and relatives interaction is task-orientated, superficial and routinely. Moreover, family caregivers might be too shy or too insecure to approach nursing staff. They are also afraid to disturb the nurses. The family caregivers therefore acquire knowledge and skills to care for the patients by mean of self-learning, self-awareness, past experience in caregiving, observation of health care personnel and other caregivers, and trial and error practice. Some family caregivers are not so concerned, and lack appropriate participation in the caregiving process.

Results from individual and focus group interviews, asking neurosurgeons and nursing staff about family participation in patient care, indicated that family's participation is a major concerning issue among the physicians and nursing staff, the implementation of this concept to clinical practice is problematic due to their perceptions, duties, and responsibilities. They feel unclear of what really needs to be done, especially the nurses should play the important role in encouraging family caregivers to participate in caring for the patients. The physicians and nursing staff view that family participation offers benefits to especially daily living activities of comforting and preventing the patients from complications. The participated caring model would help maximize family caregivers' competency to provide effective care to patients after being discharged from the hospital. In addition, family participation might help decrease stress and burden on part of the nursing staff as the number of traumatic brain injured patients has increased.

The head nurse does not only take responsibility for nursing service and personnel management at the Neurosurgical Ward, but she also plays a new role as a committee of the Hospital Accreditation Project, Department of Surgery. The neurosurgeons also recognise the importance of families' role in participation in health care for the patients and willingnesss to participate in this study.

Instruments

1. Instruments for research procedure

The instruments needed for the study are composed of a tape-recorder for subject interviews and group discussion, a camera, the Nursing Manual for Promotion of Family Caregivers' Participation in Caring for Traumatic Brain Injured Patients, Rehabilitation Manual for Family Caregivers of Traumatic Brain Injured Patients and the Ranchos Los Amigos Levels of Cognitive Functioning Scale (LCFS).

1.1 Nursing Manual for Promotion Family Caregivers' Participation in Caring for Traumatic Brain Injured Patients

The nursing manual consisted of three parts: the concept of family participation, participatory action research approach, and nursing provision for family caregiver participation in patient care.

The investigator originally constructed the nursing manual based on literature review, nursing experience and participants' inputs. Content validity was established through expert review, and pilot testing.

1.2 Rehabilitation Manual for Family Caregivers of Traumatic Brain Injured Patients

The rehabilitation manual for family caregivers was developed based on basic concept of cognitive retraining (Baggerly, 1986; Brillhart & Stewart, 1989; DeYoung & Grass, 1987; Sosnowski & Ustik, 1994). Its content was composed of family caregiver participation in physical and cognitive rehabilitation. These were sensory stimulation, environmental management, learning promotion and goal-directed behavior, adequate socialization skills, and vocational rehabilitation. Three experts who were two neurosurgeons and one neurosurgical nursing instructor reviewed the manual for content validity. The manual was used as a tentative booklet. At the end of the study, the complete booklet wouldl be accomplished.

1.3 Ranchos Los Amigos Levels of Cognitive Functioning Scale (LCFS)

The investigator applied the Ranchos Los Amigos Levels of Cognitive Functioning Scale (LCFS) which was developed by Hagen, Malkmus and Durham (1979) as a basis for delineating treatment approaches to increase cognitive abilities of the patients. The LCFS is a famous behavioral rating scale used as a description of eight levels of cognitive functions through brain injured persons' typical progress in hospital and acute rehabilitative care. The scale was composed of: level I no response; level II generalized response; level III localized response; level IV confused, agitated and inappropriate response; level V confused, non-agitated and inappropriate response; level VI confused but appropriate response; level VII automatic and appropriate response; and level VIII purposeful and appropriate response.

With the back-translation technique (Burns & Grove, 1993; Sithimongkol, 1995), the investigator translated the scale from the original language into the Thai language, and then a bilingual translator translated the Thai language to the original language. The two versions were administered with bilingual subjects. Five experts who were two neurosurgeons, two physiatrists, and one master's prepared clinical nurse specialist reviewed the content validity of the Ranchos Los Amigos Levels of Cognitive Functioning Scale (LCFS).

2. Instruments for data collection

The instruments for data collection comprised of (1) General Information Questionnaire, (2) Family Caregiver Participation Preference, Actual Participation and Satisfaction with Participation in Patient Care, (3) An Interviewing Guide of Participant Perceptions, (4) Participatory Process Evaluation Guide, and (5) Patient Recovery Assessment Tool including Modified Disability Rating Scale, and Complication Inventory Tool. Details of each instrument are presented as follow:

2.1 General Information Questionnaire

2.1.1 Family caregiver's general information questionnaire contained a checklist of demographic and socioeconomic characteristics of a primary caregiver. These included age, gender, vocational education, marital status, occupation, monthly income, economic status, and relationship with the patient. The family caregiver was also asked to answer the questions about self-perceived health, experience as a hospitalized caregiver, self-defined caregiver role, assistant person, and hometown.

2.1.2 Nursing staff demographic questionnaire contained a checklists of nursing duty, gender, age, educational level, marital status, employment in nursing, work experience in the neurosurgical ward, monthly income and economic status.

2.1.3 Patient general information inventory included open-ended and structured question. It contained checklists of demographic and socioeconomic characteristics of a patient. These are gender, age, marital status, educational level, occupation, monthly income and economic status. The questions also included the information about traumatic injury history, patient's condition, and medical history.

The investigator used the questionnairs to obtained general information of the participants at the time they entered to the study after the project had been explained to the participants, and they agreed to participate in the project.

2.2 Family Caregiver Preference, Actual Participation and Satisfaction with Participation in Patient Care

The investigator originally constructed the questionnaire to determine the family caregiver's needs, actual participation, and satisfaction with participation in patient care based on literature review, clinical experience, and an interview of ten family caregivers. The interview focused on family needs and participating experience in caring of the brain injured patients in a hospital setting. The checklist related to self-evaluation were in the form of response choices in a four-point rating scale of three themes. They were family caregiver preference, actual participation and satisfaction with participation in patient care. All four columns are defined as the first column containing 30 items in which each statement was a feature of the participating activities. The series of statements included five dimensions: a) information seeking (6 items), b) decision making (4 items), c) negotiation (5 items), d) caring practice (10 items), and e) evaluation of care (5 items). Family caregiver were asked to indicate the level of each activity they wished to get involved in the second column, ranging from 'really need' to 'no need at all' on a four-point rating scale. The participants denoted how often they were involved in each activity in the third column by using a four-point rating scale, ranging from 'usually practice' to 'no practice'. The family caregivers were also asked to evaluate the satisfaction with the role they had played in patient care in the fourth column. A four-point rating scale, ranging from 'highly satisfaction' to 'no satisfaction', was applied to rate their satisfaction with their actual participation.

Total scores for each theme of family caregiver preference, actual participation, and satisfaction with participation in patient care ranged from 30 to 120. The higher scores of each scale indicated separately the higher needs, higher actual practice and higher satisfaction with participation in patient care. Means of sum variables were used to describe the results (maximum 4).

Six experts from the nursing faculties reviewed the instrument for content validity. When the instrument was given to 30 family caregivers of brain injured patients to check for the reliability using Cronbach's coefficient alpha, it was found that the reliability for family caregiver preference, actual participation, and satisfaction with participation in patient care were .90, .93, and .91, respectively. These results indicated an internal consistency of the instrument.

The family caregiver were asked to complete the questionnaires two times—first, after they responded to the initial interview at the day of study enrollment, and second when they were discharged from the project. The test took about 20-30 minutes. The investigator used interviews and assisted the family caregivers with literate difficulties to complete the questionnaires. The interview questions were similar to the questionnaire but they allowed for further clarification of the yes and no answers followed by the rating of the level of their needs, actual participation and satisfaction in patient care.

2.3 An Interviewing Guide of Participant Perceptions

An interviewing guide was conducted to gain an understanding of participants perception about family participation in patient care. It was a semi-structured interview with the combination of broadly-framed open-end questions followed by more specific probes. For example, the family participants were asked "Will you be able to join, if you are invited to take part in patient care." followed by probes, such as, "What areas of involvement do you wish to assist the patient?" Thus, while the questions were designed to address a given set of topic areas, they could be expanded and modified as new or unexpected issues of relevance emerged during the individual interviews. In one interview, the focus became the perception of being a participant to participate in care.

Individual interviews' data were collected at initial participant from entering into the study through the time they were discharge from the project. The interviews lasted about one hour. It was audio recorded, and complete written transcriptions were made immediately after each interview. The data were analyzed to identify relevant themes or categories embedded in the text.

2.4 Participatory Process Evaluation

A concept of CIPP (Context, Input, Process, Product) model (Stufflebeam, 1971) and reflection techniques (Chuaprapaisilp, 1998) were utilized to guide and design strategies for evaluation the participatory process. The process evaluation provided the investigator and the participants with information needed for anticipating and overcoming procedural difficulties, for making preprogram decisions, and for interpreting outcomes.

Participant observation, individual interviews, and group discussion were used to collect various information. There were relationships and interaction among participants, communication, an understanding and consensus toward the planning aims of participants and others who were affected by the program. Also, sufficient resources, facile materials, and humen resources were recorded. These information were used to provide periodic feedback to persons responsible for decision pertaining to implementation of the trial, and modification of previous structuring decision as necessary. Regular feedback meetings between the investigator and key informants were conducted to evaluate the process twice a month.

2.5 Patient Recovery Assessment Tools

The Modified Disability Rating Scale, Complication Inventory Tool, and length of hospital stay were used to evaluate all patients' recovery.

2.5.1 Modified Disability Rating Scale. Rappaport and colleagues (1982) develpoed the Disability Rating Scale (DRS) to assess the level of head injured patient's awareness and self-care functioning. The DRS scale is a brief measurement of general functioning including the Glasgow Coma Scale (3 items), cognitive ability for feeding, toileting and grooming (3 items), degree of independence from attendant care (1 item), and employability (1 item). The range of possible scores is between 0 and 29 which are defined as normal and maximum disability, respectively.

In consideration of validity and reliability of the original Disability Rating Scale (DRS), the inter-rater reliability method was used to evaluate reliability. Its correlation between pairs of 3 raters who independently rated 88 head injury patients ranged between .97 and .98 (Rappaport, et al, 1982).

Hall and others (1985) examined concurrent validity of the Disability Rating Scale (DRS) by correlating DRS score with scores simultaneously obtained from Glasgow Outcome Scale (GOS) at two time intervals. The DRS and GOS scores of 70 head injured patients were significantly correlated at admission (r = .50) and discharge (r = .67). The authors claimed that the DRS was a more sensitive measure of recovery than GOS (71% of patients showed improvement on the DRS, while only 33% did on the GOS).

Gouvier and coworkers (1987) reported the comparison between the Disability Rating Scale (DRS) and the Rancho Los Amigos Levels of Cognitive Functioning Scale (LCFS) in terms of test-retest and inter-rater reliability, and of concurrent and predictive validity. Forty head-injured patients were assessed using the DRS and the LCFS four times weekly throughout their rehabilitation during hospitalization. The results showed that validity and reliability of the DRS was higher than that of the LCFS.

Intorn (1996) used the Disability Rating Scale (DRS) within 3 categories to predict discharge outcome of 25 head-injured patients. Reliability of the scale was evaluated by the inter-rater reliability method. The correlation between pairs of the researcher and the first rater was .94, and the researcher and the second rater, who independently rated 10 head injured patients was .82.

In this study, the investigator used the Modified Disability Rating Scale within 3 categories. The measurement consisted of (1) arousability, awareness and responsitivity; (2) cognitive ability to handle self-care functions; and (3) physical dependence upon others. The scale scores were converted to the Rappaport's DRS scores.

(1) Arousability, awareness and responsitivity modified from Glasgow Coma Score (Teasdale & Jennett, 1974) is an internationally accepted standard for assessing severity of injury. It is normally used to assess the neurosurgical patients in the hospital. It includes 3 items which are eye opening, best verbal response, and best motor response. Lower scores indicate greater degree of impairment.

Eye opening:	Spontaneous opening	= 4 score
	To speech	= 3 score
	To pain	= 2 score
	None	= 1 score
Best verbal responses:	Oriented	= 5 score
	Confused	= 4 score
	Inappropriate words	= 3 score
	Incomprehensible sounds	= 2 score
	None	= 1 score
Best motor responses:	Obey commands	= 6 score
	Localize pain	= 5 score
	Non purposeful	= 4 score
	Flexion to pain	= 3 score

Extension to pain = 2 score

None = 1 score

(2) Cognitive ability for self-care activities is rated only the degree to which a patient knows how and when to perform functions relating to feeding, toileting and grooming, and each items is rated separately (Rappaport, et al., 1982).

Completion of 4 scores means the patient continuously shows awareness that he or she knows how to feed, toilet, or groom self and can convey unambiguous information that he or she knows when this activity should occur.

Part of 3 scores means the patient intermittenly shows awareness and intermittenly conveys reasonably clear information that he or she knows when the activity should occur.

Minimum of 2 scores means the patient shows questionable or infrequent awareness that he or she knows in a primitive way of how to do the activity and shows infrequently by certain signs, sounds or activities that he or she is vaguely aware when the activity should occur.

None (1 score) means the patient never shows obvious awareness that he or she knows how to do the activity and when the activity should occur.

(3) Level of functioning or dependence on others is rated in terms of physical dependence. This scale was modified from the item of perception of patients toward the level of independence, Functional Independence Measure (FIM). The scale is composed of

No helper: Completely independence (timely, safely) = 6 score

Modified independence (device) = 5 score
Helper: Minimal assistance (< 25%) = 4 score
Moderate assistance (25% - 50%) = 3 score
Maximal assistance (>50% –75%) = 2 score
Total assistance (75% – 100%) = 1 score

Scores of the scale range from 7 to 33, with the higher score indicating the higher ability.

The Modified Disability Rating Scale was translated from the original language into the Thai language by the investigator, and then a bilingual translator back translated from the Thai language into the original language. Two versions were organized by bilingual subjects. Six experts who were two neurosurgeons, two physiatrists, and one master-prepared clinical nurse specialist reviewed it for content validity. Following the content validity review, the instrument was tested by 3 trained raters who were one investigator, one neurosurgeon, and one neurosurgical registered nurse. Inter-rater reliability was computed by using the Cohen's kappa method. Reliability between pairs of 3 raters, who independently rated 10 brain injured patients, ranged from .94 to .96, indicating a reliability of the instrument.

2.5.2 Complication Inventory Tool contains the checklists of patient's complications within 4 categories. There were respiratory infection, urinary infection, pressure sore, and contracture.

1) Respiratory infection:

a. new chest x-ray shows lung pathology such as infilltration, consolidation, cavitation, or pleural effusion, and

b. two out of four clinical manifestations and diagnostic examinations are shown as follows: (a) fever ($T \geq 38°C$); (b) productive cough with greenish or rusty spots; (c) crackles or crepitation, and/or dullness over area of consolidation; and (d) leukocytosis: WBC > 10,000 cell/mm with neutrophil > 80%.

2) Urinary infection:

a. fever ($T \geq 38°C$) and/or pressing pain at supra-pubic area;

b. urinalysis shows white blood cell count ≥ 10 WBC/ high-power field, and/or urine culture shows bacteriuria $\geq 10^5$ colonies/ml.

3) Pressure sore is localized damage to the skin caused by disruption of blood supply to the area. It is usually caused by pressure, shear or friction, or a combination of any of these. It can be assessed by The American National Pressure Ulcer Advisory Panel (1989) considering initial stage II and beyond.

Stage II: Partial-thickness loss involves epidermis and/or dermis. The ulcer is superficial and may be seen as a blister, abrasion or crater.

Stage III: Full-thickness wound involves epidermis, dermis and subcuticular layer. The ulcer shows as a crater with or without undermining.

Stage IV: Extensive destruction involves other tissues such as muscle, tendon or bone.

4) Contracture is deformities resulted from both persistent lack of motion and active nonfunctional posturing.

Five experts who were two neurosurgeons, one physiatrists, one physician specialist in infectious disease, and one master's-prepared clinical nurse specialist in neurosurgical nursing reviewed the content validity of the complication inventory.

The process of data collection

The process of data collection using participatory action research was divided into 4 phases: 1) preparation phase, 2) action phase, 3) evaluation phase, and 4) model development.

1. Preparation phase

An initial phase involved many elements, including selection of the setting and necessary materials, obtaining administrative support, raising awareness, organizing key informants, and conducting the pilot study. These are discussed below:

1.1 Selection of the setting. Selection of the research setting is an important step, as the access to and also characteristics of participants are considered. In the early stages, the investigator decided to go to a Neurosurgical Ward and usually visited a site to seek understanding of the current situation. The investigator utilized both qualitative and quantitative data collection techniques to gain knowledge about the history of the organization, structure, culture and problem areas.

Participant observation focusing on the current clinical nursing practice recurred in the Neurosurgical Ward. These were management style, atmosphere, interpersonal relationships at work and interaction among nursing staff, patients, families and other health care providers. The in-depth interviews were conducted in three different groups of nursing staff, physicians, and family caregivers to reveal their feelings, opinions, experiences, satisfaction, their concerns with the present practice, influencing factors, improvement plan, and their expectations.

Simultaneously, information taken from informal discussions with the nursing staff at the Neurosurgical Ward (6/1) and the General Medical Ward (8/1) where it was managed differently was collected. Information from literature review was included in the overview of the current research since it provided the investigator with some areas of concern. In addition, a retrospective study of traumatic brain injury at the hospital in the year of 1997 was conducted to obtain historical background evidence.

Several months into this phase, the investigator obtained information providing a more holistic view of both positive and negative aspects of working in the ward. It reflected the elements of the conceptual model guiding this project. They were the approaches, participation, influence, and individual and group abilities that were important factors influencing care providers' perceptions, changes and their effects on patient recovery, and satisfaction with care provision. This information was also used to as baseline data for later comparisons to evaluate the intervention outcomes.

While providing an assessment of current situation, these approaches also helped develop trusting relationships between the investigator and possible participants who were the crucial factor in the study.

1.2 Development of the manuals, and instruments for data collection. The data gathered through clinical experience, baseline survey and literature review were used as the baseline data for constructing the manuals and the research instruments previously mentioned. The investigator trained to use the entire strategies and scales. The instruments were used to collect data and evidence which were explicit by the process and outcome of the study.

1.3 Obtaining administrative support. The investigator proposed the research project to immediate superiors, who were head nurse, nursing supervisor, neurosurgeons, and director of Nursing Services Department for permission and complete preparation of the study. The project explanation included the objectives, the process of program planning, interventions, and evaluation, as well as cost and benefits of the study.

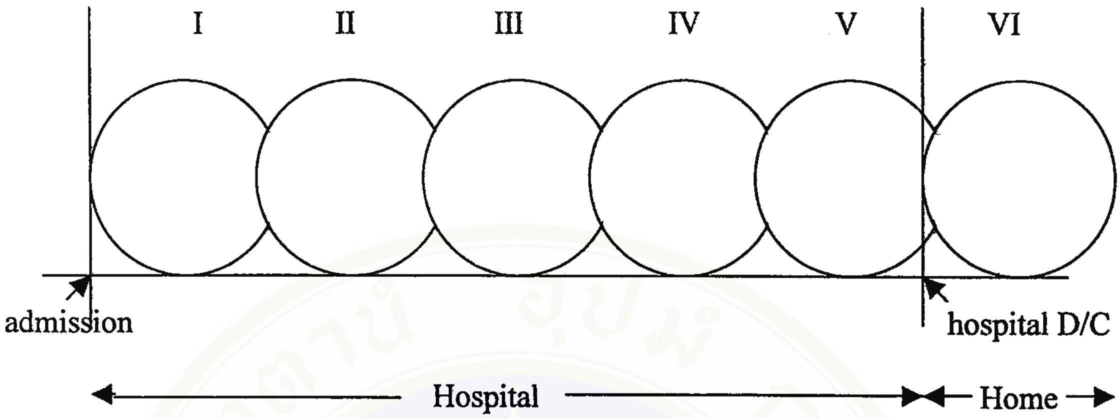
1.4 Raising awareness. A workshop on "Participatory Action Research and Family Participation in Patient Care" was conducted on May 27, 1999. It was based on the collaboration among the investigator, thesis advisors and the director of Nursing Services Department to enable the nurses to better understand the project, to gain collaboration for implementation and to empower them. A subsequent workshop enabled most nursing staff to raise their concerns and understanding of the collaborative research. The director of Nursing Services Department played the crucial role to enhance them, as she took part in expenses, promotion and pursuit of the project progress.

Simultaneously, hospital policy concerning the Hospital Accreditation was included to contribute the quality of health care services which was a significant motivator to encourage nurses to improve the quality of clinical nursing practices. Seminars and workshops on Hospital Accreditation were organized for health care providers to gain knowledge and to empower them.

1.5 Key informant organization. The meeting among an investigator and nursing staff was held to discuss the current situation, to share information, and to seek their agreement to provide assistance. The investigator described the current situations based on the data obtained from the baseline surveys, identified strengths and weaknesses, and priorities areas for improvement. The nursing staff were allowed to discuss all the problems that arose from the baseline surveys and planned for improvement. This permitted a better understanding on many problems which occurred in the ward that they did not know or ignore although they were considered serious problems in the ward. The nursing staff were invited to change any aspect they felt discomfortable to share with others. Also, they were requested as key informants to join the investigator to carry out the study. They accepted the request and agreed to share the information about the current practice in the ward with others, and five senior nursing staff including the head nurse were pleased to take the role of key informants in the study.

Additionally, several formal and informal discussions among the investigator, key informants, nursing supervisor, neurosurgeons, physiatrist, physical therapist, and neurosurgical nursing instructor were held to discuss the rationale for collaboration, objectives, actions for collaboration, benefits of the project, and feasibility. These were taken into considerately group discussions which aimed to seek their agreement, and to gain collaboration for the project implementation. Exchange of information and ideas were encouraged among the groups.

1.6 Pilot study. Based on the suggestion from thesis advisors, the pilot study was developed to validate the impressions and to identify areas for the study. It also was conducted to assist the investigator to gain confidence and skills in collecting and analyzing data. The investigator and key informants conducted a pilot study at a Neurosurgical Ward. Three family caregivers of three traumatic brain injured patients participated in the process through the participatory action research spiral of steps, which was composed of plan, action, observation, reflection and revision plan. The result was then used to develop a tentative model for family caregivers' participation in caring of traumatic brain injured patients (see Figure 2).



Phase 1. Preparation for participation in care
Phase 2. Situational assessment and mutual care plan
Phase 3. Caregiver's ability development
Phase 4. Maintaining the caring ability
Phase 5. Discharge planing
Phase 6. Facilitating the transitional care

Figure 2. Tentative model for family caregivers' participation in caring of traumatic brain injured patients

2. Action phase

Following the study protocol approved by the institutional review board, the collaborative activities were implemented as follows:

2.1 Participants of 30 nursing staff including 5 key informants were invited to participate in the study. They were asked to complete the demographic information questionnaire and interviewed using the interview guide to gain insights into their understanding toward family participation in patient care. This process lasted an average of one hour. In this step, the process of negotiable access to participants was long and arduous. Although most participants were willing to share their idea and experience, a few attempted to avoid a dialogue due to uncertainty.

Thirty minutes of informal group discussions during meal break, and in the afternoon, were daily applied to build trusting relationships between the investigator and the practitioners. General information, jokes, and nursing experience were mentioned. Subsequent discussions had provided better relationship and shared information among them.

2.2 The investigator organized a nursing conference to increase knowledge and nursing skills for participatory action research, and family participation. The subjects concerning philosophy, politics and purposes of the participatory action research approach, and family participation were reviewed. Principles of collaboration and implementation for the setting were especially emphasized. Another important issue on implementation collaborative activities was also used as the tools. These were the Ranchos Los Amigos Scale, Patient Recovery Assessment Tool, and Nursing Manual for Promotion of Family Caregiver Participation in Caring for Traumatic Brain Injured Patients. The investigator distributed the tools to nursing staff, explained to them how to use these tools, and allowed them to express their opinions, and discussed these tools.

2.3 The investigator and key informants worked together to select possible family caregivers using the inclusion criteria previously mentioned. After having identified the family caregivers, the investigator described the purpose of the study to the family caregivers and invited them to participate in the study. Explanation and consent form were given to them. After obtaining informed consent or verbal agreement, the investigator interviewed the family caregivers concerning patient conditions, impacts, participation in care, participant role, influencing factors, feelings and expectations of participation in care. The interviews lasted an average of one hour. Afterwards, the family caregivers were asked to answer the questionnaires regarding the general information and their preference, actual participation and satisfaction with participation in patient care. The investigator explained the concept of family participation to the caregivers, aiming to promote understanding, establish trust, and help the family caregivers to develop realistic expectation. Patients who were admitted into the project were assessed for thier conditions using the Ranchos Los Amigos Scale and Patient Recovery Assessment Tool.

2.4 The nursing staff implemented the collaborative project through the tentative model as follow:

Phase 1. Preparation of family caregivers for participation in care

1. Building therapeutic relationships to gain mutual trust and respect
2. Providing information about patient's conditions, treatments and outcomes to reduce family's anxiety and fears
3. Providing emotional and psycho-spiritual support
4. Consulting and facilitating family caregiver about their concern

Phase 2. Situational assessment and care plan together

1. Mutual goal setting and writing care plan together
2. Sharing information about the strategies for implementation
3. Empowering family caregiver to chioce and decision-making

Phase 3. Family caregiver's ability development

1. Teaching and training with collaboration of other care providers
2. Increasing family confidence in their own abilities using a booklet
3. Providing emotional and psycho-spiritual support
4. Encouraging family caregiver to involve in patient care

Phase 4. Maintaining the caring ability

1. Continued knowledge and information provision
2. Maintaining the family caregiver's ability to care for the patient
3. Providing emotional psycho-spiritual support
4. Collaborative evaluation

Phase 5. Discharge planning

1. Understanding and acceptating potential disability of the patient
2. Reviewing knowledge and skill training for continuity of care with collaboration of other health care providers
3. Empowering family caregiver and enhancing their own confidence
4. Basic guideline regarding further problem solving
5. Seeking for the support resources

Phase 6. Facilitating the transitional care

1. Consultating and advising regarding problems and solutions
2. Enhancing family confidence and motivation by telephone contact

As for the collaborative activities mentioned above, the participants including nursing staff and family caregivers performed them through the action spiral which consisted of assessment of current situations, action plan, implementation and reflection. These were organized throughout the process until the participants' appropriate and satisfactory model could be achieved.

1. Joint assessment to current situations
    - 1.1 Family caregiver's perception regarding patient's condition, needs and caregiver's role
    - 1.2 Family readiness and confidence in their own ability to care

- 1.3 Factors promoting and inhibiting family caregiver's ability
- 1.4 Collaborative activities for care

2. Action plan
   - 2.1 Considering associated factors for care
   - 2.2 Mutual goal setting
   - 2.3 Jointly identifying strategies for implementation to attain goal
   - 2.4 Sharing information about collaborative activities
   - 2.5 Conclusion of collaborative activities together
3. Implementation and reflection
   - 3.1 Implementation of action plan
   - 3.2 Interval reflection on the process of collaboration
   - 3.3 Revising and reimplementing action plans

Figure 3: Sharing of information among family caregivers and health care providers.

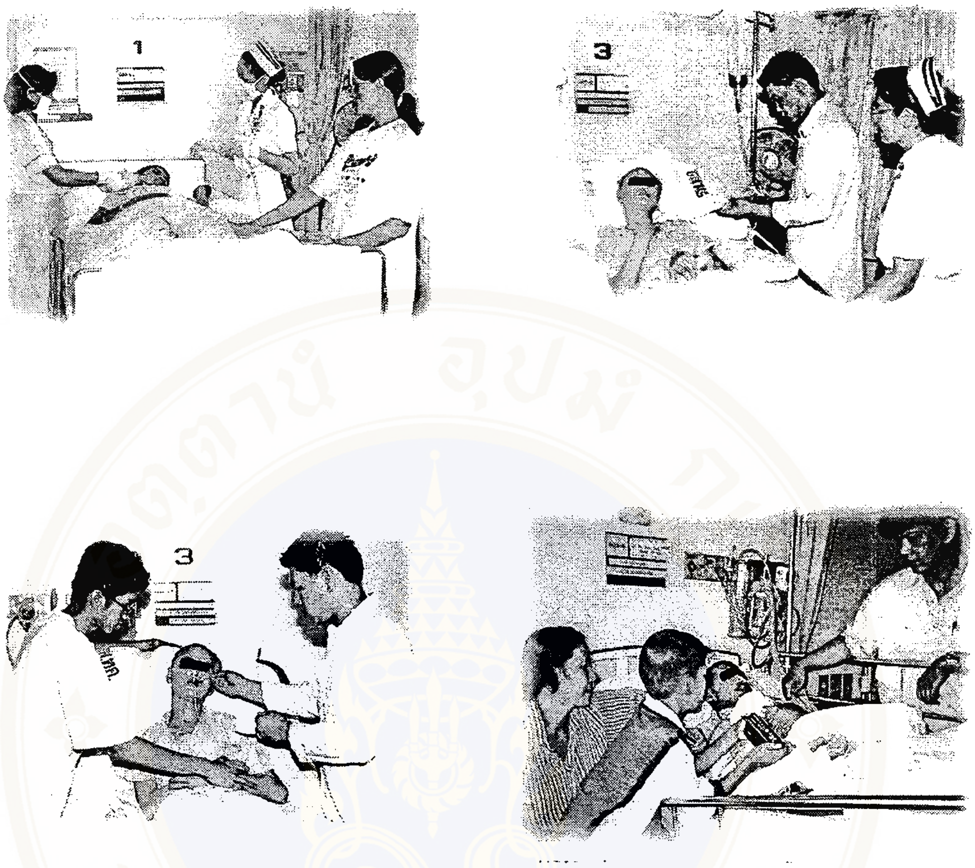


Figure 4 : Sharing of care

Figure 5 : Interval reflection

3. Evaluation phase

The investigator concluded the process and outcomes of the study. Data were analyzed to summarize a satisfactory model and the knowledge gained. Family caregiver's satisfaction with participation in care was evaluated using the questionnaires, individual interviews and participants observation. Patient's Recovery Assessment Tool was applied to evaluate patient recovery level. Individual interviews and group discussions were organized to assess nursing staff's satisfaction with participation in patient care. Interval reflection, behavioral observation and records, and comments of participants and other health care providers were conducted to evaluate the collaborative process. The results were discussed among the investigator, key informants, and participants in the meeting.

4. Model development

Qualitative and Quantitative data were analyzed to summarize a model. The final meeting among the investigator, key informants, nursing staff, neurosurgeons, traumatic brain injured patient, family caregivers and thesis advisor was conducted to validate the research results and the model on May 17, 2001.

The role of investigator

In monitoring the study, the investigator played the role of a facilitator, consultant, and researcher to help participants evaluate their practice, plan and implementation of the project. It included self-reflective discussions, goal setting and any other changes to evaluate the project's outcome. Expert clinician and educator was a significant role the investigator experienced in this setting, which involved the complex health issues and specialization. Working as a practitioner was necessary at the crisis time, such as life-treatening, cardiac pulmonary resuscitation and endotracheal intubation, as well as the time nursing staff or family caregivers required due to the large number of critically brain injured patients, hasty work and heavy overload. Moreover, the investigator performed the role of a coordinator to obtain suggestions and directions from physicians and other care providers such as physical therapists and social workers.

The investigator used the following strategies to improve nurses' caring attitude and behaviors.

1. Reflecting on quality of care. The investigator encouraged the nursing staff to gain an understanding of the current clinical nursing practices and its strength and weakness. The alternative care strategies were presented in order to develop the nursing services. Interviews were conducted to extract the reflection from each nurse. The data were collated and used as seed idea in the focus group.

2. Providing information and knowledge. The nursing staff would receive the information on clinical practice as well as the skill to establish the relationship with the patients and families. The investigator was always on site to observe the caring situation and provide consultation as needed.

3. Role modeling. The investigator and key informants demonstrated the clinical nursing practices specified in the tentative model for the nursing staff. We would assist in the implementation of the model. This approach would encourage the nursing staff of the viability of the participated caring model. The approach emphasized on the freedom of practice and sole responsible was placed in the nurse's hand to maximize the empowerment of the program.

4. Providing support. The nurse was encouraged to have compassion of care toward the others that included the patients, the family caregivers and relatives, and the colleagues in order to establish the trust and collaboration. The supportive environment could maximize the participation of all concerns. The investigator and the key informants would play the devoted assistant role in the participation process.

5. Reinforcement. The reinforcement measures were implemented to assure the nursing staff of the effectiveness of the model. These included: 1) encourage the patient and family caregivers to come to see nursing staff and other patients and families when they turn to the physician's follow-up appointment; 2) provide the feedback such as the positive of care outcomes, the complimentary words that reflected the gratitude from the patient, the family caregivers, as well as the colleagues; 3) encourage the nursing staff to present the information concerning the model development and the telephone contact result at the hospital conference on the 15th of March 2000 and March 21, 2001; and 4) nursing leaders especially the director of the Nursing Service Department are the significant motivators in encouraging and continue supporting nursing staff to improve the quality of care.

Protection of human subjects

The research proposal was submitted to, and approved by, the Thesis Proposal Examination Committee, Faculty of Nursing, Mahidol University. Permission was obtained from Directorate of Medical Services of the Royal Thai Air Force and the institutional review board to conduct the study at Bhumibol Adulyadej Hospital.

Consequently, the nature and process of the study were explained to nursing staff, other health care providers, such as neurosurgeons and physical therapists, who involved in the project and family caregivers to request for their collaboration. After enrollment in the study, the investigator described the objectives and process of the study and explained to them through the reading of the consent form. The family caregivers were informed that their patients were free from physical risks as a result of their participation in this study. They were also told that they could feel free to withdraw from the study at any time without negative effects on the care the patients would receive. The investigator promised to share the data with them throughout the study, and the data would not be published without their permission. Throughout the study process, the investigator made every attempt to avoid any possibility of discomfort, physical harm or excessive response burdens on the participants.

Data collection

The investigator collected data using the following methods:

1. **Qualitative data:**

1.1 Participatory observation was applied so that the investigator could understand the current situation and collaborative process among the participants. The observation and transcription of data collection were conducted throughout the project process.

1.2 An interview guide and unstructured interviews were organized to help the investigator understand in detail the current situation and collaborative process among the participants. The interviews lasted an average of one hour. They were tape-recorded and complete written transcriptions were made immediately after each interview. All transcriptions were compared with the tape-recorded interviews for accuracy, and notes were taken for the participants' voice intonations, body languages, and emphases. Data gathering from transcriptions and observation notes were reviewed repeatedly for identification of themes. Significant thematic statements were selected, and thematic cluster were identified and grouped to describe the situation (Strauss & Corbin, 1990).

1.3 Reflection were used in reflective discussions on commitment, participant actions, and steps of model development to give participants opportunity to explore what each one thought and felt about any other particular issue that they found useful for group discussions.

The investigator and key informants aimed to meet twice a month to discuss the data obtained from the questionnaires, interviews, and reflective practice. The nursing staff in the Neurosurgical Ward were divided into five groups. The first group consisted of one head nurse, and five senior nurses who worked a day shift. The rest consisted of two registered nurses, a technical nurse, and three nurse aids, who rotated from a night shift to evening shift, to a day shift and day off. Each of their shifts took two days, which enabled them to attend the regular meetings. The participants decided that all should meet once a week from 02.00-03.00 p.m. and each group met with the investigator once a month. Since the patient's lengths of hospital stay were different, the family caregivers would attend the group discussion once a week when they first entered into the study until their patients were discharged from the hospital.

The number of the critically brain injured patients of 10-12 cases on the endotracheal tube with respirator, uncertainty and hasty heavy overload induced the obstacle to the meeting plan. The investigator collaborated with the participants to adjust the schedule. The meeting therefore varied with time and amout of work involved. The neurosurgeons and physical therapists were invited to involve in the process. Tape-records and transcriptions were used to collect data as well.

2. Quantitative data:

2.1 The questionnaires consisted of general information and the family caregiver preference, actual participation, and satisfaction with participation in patient care. The investigator used the general information questionnaires to explore the participants including nursing staff, patients and family caregivers at the time of study enrollment. The rest evaluated family caregivers' needs, actual participation, and satisfaction with participation in patient care at a two-time interval—at the time of study enrollment and the time when they were discharged from the project.

2.2 Assessment of the patients' recovery was conducted by using the of Modified Disability Rating Scale, and the Patient Complication Inventory Tool. The scales were regularly used once a week, starting when the patients entered into the study until they were discharged form the hospital.

Data analysis

1. **Qualitative data.** The investigator used the technique of constant comparative analysis (Glaser & Strauss, 1967; Strauss & Corbin, 1990) to analyse proceeding concurrently. It was carried out through coding and developing themes and a model. Triangulation techniques (Banik, 1993; Duffy, 1987; Mitchell, 1986) were also utilized to improve the validity.

2. **Quantitative data.** The Statistical Package for the Social Sciences (SPSS 8.0 for Windows) was used to analyze the quantitative data.

1.1 The descriptive statistics was applied to describe the general information including socio-demographic characteristics of the nursing staff, family caregivers and the traumatic brain injured patients.

1.2 Paired T-test was used to test the differences in the degree of family caregiver's preference, actual participation and satisfaction with participation in patient care between the time of study enrollment, and the time the patients were dismissed from the project.

1.3 Paired T-test and descriptive statistics were utilized to examine the differences in the level of the patients' recovery between the time of study enrollment and the time of the patients' discharge from the project.

CHAPTER IV

RESULTS

The results of this study are presented in 3 consecutive parts: 1) characteristics of the participants; 2) model for family caregivers' participation in caring for traumatic brain injured patients; and 3) the scenario.

Characteristics of the participants

This part includes the profile and the demographic characteristics of the participants and factors related to traumatic brain injury of the patients.

1. Nursing staff information

The nursing staff consisted of 13 registered nurses (RN), 5 technical nurses (TN) and 12 nurse aids (NA). Their ages ranged from 21 to 47 years with a mean age of 29 years old. The majority of nursing staff were single females aged between 21-29 years old and finished a bachelor's degree. Most of them had work experiences in the Neurosurgical Ward for less than 5 and 3 years, respectively. The finding revealed that most of them had personal monthly income ranging from 4,500 to 19,830 bath, which was sufficient income for a day-to-day living but not for saving. Only some reported that this amount was sufficient and good for saving. The details are displayed in Table 1.

Table 1 Demographic characteristics of the nursing staff

Characteristics	RN (n=13) number	TN (n=5) number	NA (n=12) number
Gender			
Male	-	5	-
Female	13	-	12
Age (mean = 29 years)			
20-29	4	4	11
30-39	5	1	1
40-49	4	-	-
Marital status			
Single	9	5	8
Married	4	-	4
Education			
Secondary level	-	-	9
College, diploma	-	5	3
Bachelor's degree	13	-	-
Employment in nursing			
≤ 5 years	4	4	8
6-15 years	3	1	4
16-25 years	5	-	-
> 25 years	1	-	-
Work experience on neurosurgical ward			
≤1 year	5	3	3
2-3 years	2	1	4
4-5 years	3	-	1
> 5 years	3	1	4
Monthly income (Thai baht)			
< 5,000	-	-	12
5,001 - 10,000	4	5	-
10,001 - 15,000	5	-	-
15,001 - 20,000	4	-	-
Economic status			
Sufficient income without saving	9	1	8
Sufficient income with saving	4	4	4

2. Family caregivers information

The family caregivers consisted of 16 women and 6 men. Their ages ranged from 19 to 53 years old with a mean age of 36.5 years old. The majority of them were married and finished elementary school. There were 6 groups of occupation: traders, employees, government officers, agriculturists, housewives and students. Their monthly income ranged from 3,000 to 26,000 baht, which most of them said that it was sufficient income to survive but not for saving. Most of them were spouses and parents, and only one person was the patient's child.

The majority of the family caregivers had previous experience in caring for other relatives in the hospital and had other family members and relatives in tow to take their turn in the hospital. The perceived health before and during the care of these caregivers was healthy. Most of them lived in Bangkok and nearby provinces within the central region. Few were from the northern, the northeastern, and the southern parts of Thailand. The details are illustrated in Table 2.

Table 2 Demographic characteristics of the family caregivers (n = 22)

Characteristics	number	Characteristics	number
Gender		Current marital status	
Male	6	Single	6
Female	16	Married	15
		Divorced	1
Age (mean = 36.5 years)			
≤ 20	3	Education	
20-39	7	Elementary level	15
40-59	12	Secondary level	4
		College diploma	1
		Bachelor's degree	2

Table 2 Demographic characteristics of the family caregivers (n = 22) (continued)

Characteristics	number	Characteristics	number
Occupation		Previous experience with a relative in the hospital	
Trader	6	No	7
Employee	6	Yes	15
Govermental official	4		
Agriculturist	4	Self-defined caregiver role	
Housewife	1	Sole caregiver	5
Student	1	Shared caregiving	17
Monthly income (Thai baht)		Assisting person	
≤ 5,000	11	Spouse	6
5,001 - 10,000	7	Father/mother	5
10,001 - 15,000	2	Adult child	1
15,001 - 20,000	1	Sister/brother	5
≥ 20,000	1	Others	5
Economic status		Self-perceived health before taking caregiving role	
Insufficient income	1	Healthy	14
Sufficient income without saving	20	Unhealthy	8
Sufficient income with saving	1		
		Self-perceived health during caregiving role	
Relationship to patient		Healthy	18
Spouse	7	Unhealthy	4
Father/mother	7		
Adult child	1	Hometown	
Sister/brother	4	Bangkok	8
Daughter-in-law	1	Central region	8
Aunt	2	Northern region	2
		Northeastern region	2
		Southern region	2

3. Characteristics of the traumatic brain injured patients

3.1 Socio-demographic characteristics

The patients with traumatic brain injury in this study consisted of 13 men and 7 women aged between 13 to 72 years old with a mean age of 35 years old. The majority of them aged between 20-39 years, were single, and finished secondary school. Before having injury, most of the traumatic brain injured patients were employees and students. Their monthly income was between 3,000 to 15,000 baht. The sources of support during hospitalization were from social welfare and governmental health card, governmental support, traffic security insurance organizations and self-support/family support. The details are shown in Table 3.

Table 3 Demographic characteristics of traumatic brain injured patients (n = 20)

Characteristics	number	Characteristics	number
Gender		Occupation	
Male	13	Employee	8
Female	7	Student	6
		Governmental official	3
Age (mean = 35 years)		Housewife	1
≤ 20	5	Unemployed	2
20-39	9		
40-59	5	Monthly income	
≥ 60	1	No income	8
		≤ 5,000	6
Current marital status		5,001 - 10,000	3
Single	11	10,001 - 15,000	3
Married	8		
Widowed	1	Sources of payment	
Education			
No schooling	1	Social welfare and governmental health card	6
Elementary level	3	Governmental support	5
Secondary level	9	Traffic security insurance	5
College diploma	6	Self and family	4
Bachelor's degree	1		

3.2 Characteristics related to traumatic brain injuries

The majority of the patients sustained brain injury from a motorcycle accident. Most of them were diagnosed as intracranial hematoma, such as epidural, subdural, and intracerebral hematoma. The severity of the injury was classified into 3 degrees with 7 mild brain injury cases, 7 moderate brain injury cases, and 6 severe brain injury cases. Eleven patients received first admission post-injury at the hospital, 5 cases were transferred from private hospitals, and 4 cases from local hospitals.

Most operations undertaken for the removal of traumatic mass lesions to improve patient mortality and morbidity were craniotomy and craniectomy. Most of the patients got prophylactic antibiotic drug with cloxacillin intravenous injection at pre-operation and a maintenance dose of 1 gms every 6 hours for 24 hours for 3 days. This drug administered was extended to 5 or 7 days for 4 patients with compound fracture or open wound. If the signs of infection had occurred, the combination of cephalosporin and aminoglycocide was given. Ten, seven, and three patients were identified according to the Ranchos Los Amigos Scale (RLAS) as level IV – VI, I - III, and VII – VIII, respectively. The details are included in Table 4.

Table 4 Characteristics related to traumatic brain injury

Characteristics	number
Cause of injury	
Motorcycle accident	17
Slippery	1
Fall	1
Falling down from the garbage truck collector	1

Table 4 Characteristics related to traumatic brain injury (continued)

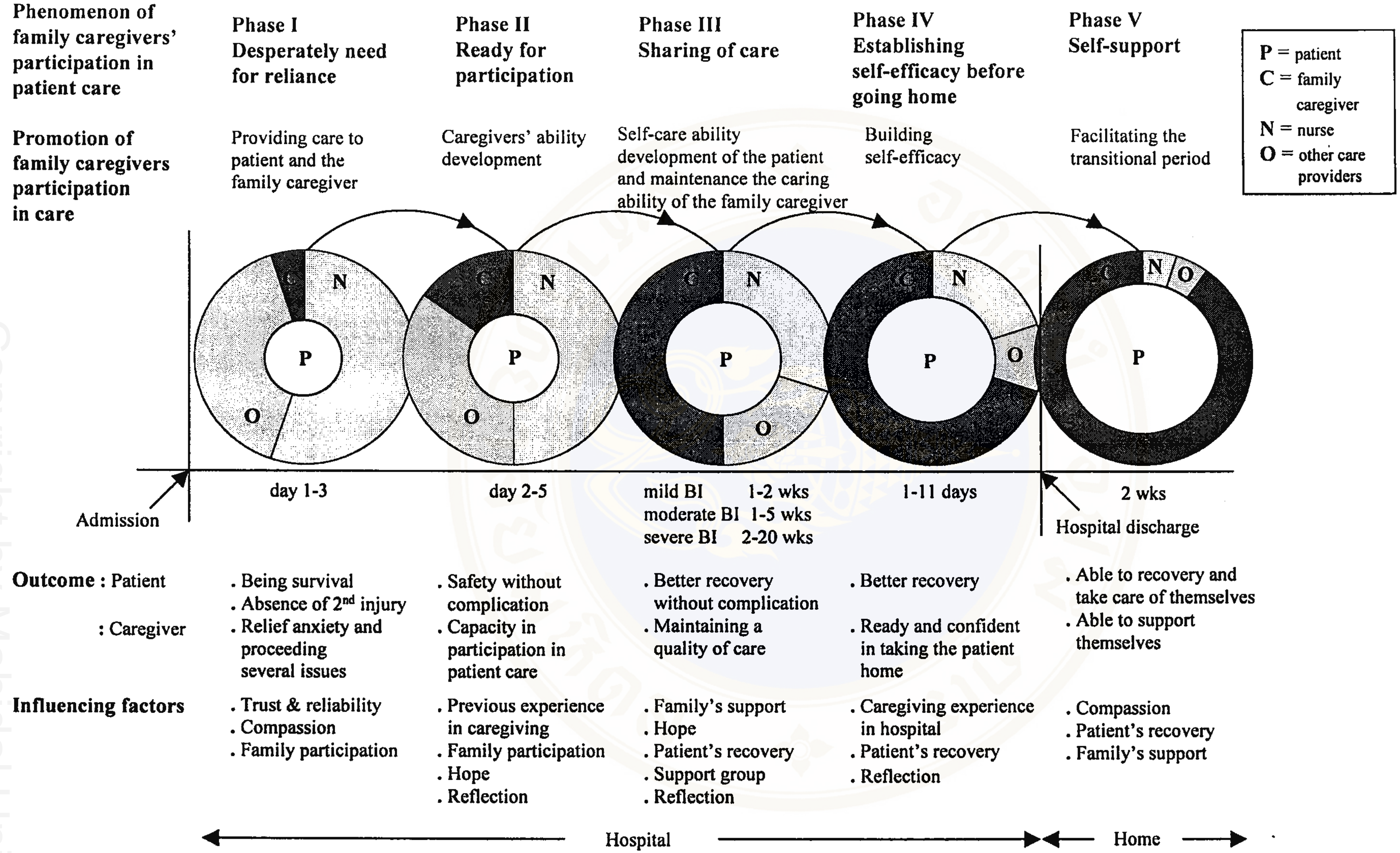
Characteristics	number
Medical diagnosis	
Intracranial hematoma	
Epidural hematoma	5
Subdural hematoma	3
Epidural hematoma & subdural hematoma	2
Intracerrebral hematoma	1
Epidural hematoma & subarachnoid hemorrhage	1
Fractured skull & intracranial hematoma	2
Intracranial hematoma & spinal injury	2
Compound depress fractured skull	1
Cerebral contussion	1
Cerebral contussion & intracranial hematoma	1
Brain swelling & fractured facial bone	1
Severity of brain injury	
Mild injury (GCS 13-15 scores)	7
Moderate injury (GCS 9-12 scores)	7
Severe injury (GCS 3-8 scores)	6
The admission	
First admission post injury at this hospital	11
Transferred from private hospitals	5
Transferred from local hospitals	4
The operations	
No operation	2
Craniotomy	9
Craniectomy	2
Craniotomy & craniectomy	2
Craniotomy & Open reduction and internal fixation (ORIF)	1
Burr hole with irrigation	1
Open reduction and internal fixation with wiring	1
Anterior fusion cloward's operation	1
Craniotomy & V-P shut & Harrington Rod instrumentation	1
Antibiotic drugs used	
Prophylactic cloxacillin injection 1 to 3 days	12
Five to seven days for compound fracture and open wound	4
Cephalosporin & aminoglycocide for infection	4

Table 4 Characteristics related to traumatic brain injury (continued)

Characteristics	number
Ranchos Los Amigos Scale (RLAS)	
Level I, II, III	7
Level VI, V, VI	10
Level VII, VIII	3

Model for family caregivers' participation in caring for traumatic brain injured patients

The model for family caregivers' participation in caring for traumatic brain-injured patients in Figure 7 was the primary research finding. This process-model began when the patients were admitted in the neurosurgical ward until the discharge and the following-up period at home. The major elements of this 5 phases-model comprised of 1) the phenomenon of family caregivers' participation in patient care that included 5 phases of action: desperately need for reliance, ready for participation, sharing of care, establishing of self-efficacy before going home, and self-support; 2) the promotion of family caregiver's participation in care consisted of: providing care to the patient and the family caregiver, caregivers' ability development, self-care ability development of the patient and maintenance the caring ability of the family caregiver, building self-efficacy, and facilitating the transitional period; 3) factors influencing the dependent care agency included trust and reliability, caring and compassion of the nurses, sharing information among family members and helping each other, caring experience, hope, reflection, support group, and the patient's recovery; and 4) the care outcomes.



Phenomenon of family caregivers' participation in patient care	**Phase I** **Desperately need for reliance**	**Phase II** **Ready for participation**	**Phase III** **Sharing of care**	**Phase IV** **Establishing self-efficacy before going home**	**Phase V** **Self-support**
Promotion of family caregivers participation in care	Providing care to patient and the family caregiver	Caregivers' ability development	Self-care ability development of the patient and maintenance the caring ability of the family caregiver	Building self-efficacy	Facilitating the transitional period
	day 1-3	day 2-5	mild BI 1-2 wks moderate BI 1-5 wks severe BI 2-20 wks	1-11 days	2 wks
Outcome : Patient	. Being survival . Absence of 2nd injury	. Safety without complication	. Better recovery without complication	. Better recovery	. Able to recovery and take care of themselves
: Caregiver	. Relief anxiety and proceeding several issues	. Capacity in participation in patient care	. Maintaining a quality of care	. Ready and confident in taking the patient home	. Able to support themselves
Influencing factors	. Trust & reliability . Compassion . Family participation	. Previous experience in caregiving . Family participation . Hope . Reflection	. Family's support . Hope . Patient's recovery . Support group . Reflection	. Caregiving experience in hospital . Patient's recovery . Reflection	. Compassion . Patient's recovery . Family's support

Figure 6. The Model for Family Caregiver's Participation in Caring for Traumatic Brain Injured Patient

The Scenario

This part elaborates 3 major factors related to the model: 1) the traumatic brain injury phenomenon, 2) the process of model development, and 3) the impacts of the model.

1. The traumatic brain injury phenomenon

The scenario from the minute the patient had an accident until the caregiver took part in the care at the hospital presented here was intended to broaden the perspective of the phenomenon under investigation. This information facilitated the understanding of the present situations and associated factors of family's participation that led to the development of effective interventions.

1.1 The traumatic brain injury

Most of the patients in this study had brain injury from accidents, especially motorcycle accidents. Only 3 patients had brain injury from other causes: one from slippery, one from falling down from the garbage truck collector, and the last had fallen from a high post while at work. These injuries caused severe brain injury in many subjects that made the patients lose their consciousness, and had decreased responses to stimuli. Some patients had shown a slight change of consciousness such as confusion, drowsiness, or irritation and some had severe headache, vomiting and hemiphegia. In some cases, the patients still were fully conscious right after the injury but gradually lost their consciousness and finally completely lost their consciousness.

Glasglow Coma Score (Neurosurgical Association of Thailand, 1997) identified three groups of traumatic brain injured patients according to their level of severity: severe brain injury (≤ 8 GCS scores), moderate brain injury (9-12 GCS scores), and mild or minor brain injury (13-15 GCS scores), respectively. The patients in this study were categorized according to Glasglow Coma Score as follows.

The severe brain injury. Six patients (4 males and 2 females) were diagnosed as having severe brain injury. Among them, 4 patients were unconscious but still had local responses to pain, while the other two had non-purposeful response when admitted in the hospital. Among these two cases, one had a high fever and rigid extremities and the other had wound infection from previous surgery, pneumonia and urinary tract infection. Of the 6 patients, 2 received surgical interventions immediately due to intracranial hematoma and 2 had nonoperative conditions (brain swelling and cerebral contussion). The remaining 2 patients had surgical interventions from other hospitals 7 and 10 days before and they received nasogastric tube feeding. All of them received intubation with a respirator, intravenous fluids, and retained Foley catheter.

The moderate brain injury. Another seven patients (6 males and 1 female) were diagnosed as having moderate brain injury. This group came to the hospital with the changes of consciousness, had local response to pain and opened their eyes when called. Some patients could follow the command, but could speak only in broken words or with confusion. One patient came to the hospital with severe headache and vomit. Six patients underwent surgery due to intracranial hematoma or compounds depress fractured skull. One patient who was referred from a private hospital and had early pneumonia did not have surgery. After surgery and treatment, every patient had gradually gained his or her consciousness and responses. They could open their eyes, follow command or localize pain and speak with confusion. Only some patients had received intubation, one of whom had left hemiphegia. Every patient had retained Foley catheter.

The mild brain injury. The last seven patients (3 males and 4 females) were classified as the mild or minor brain injured patients. Most of them came with altered consciousness, could act according to the instruction for sometimes or local responses to pain, and some spoke in confusion. Three patients remained conscious but had severe headache and two patients had vomited. All cases were found with intracranial haematoma, whereas one had concomit brain contusion. Only six patients had brain surgery to remove blood clot; five of them had immediate brain surgery and only one patient was operated five days afterward. The patients who had thin layer intracranial haematoma with brain contussion received only medicine treatment. After surgery, most of them regained their consciousness and could respond to command. Some could speak fluently, but some still had confusion. This group mostly recovered soon and could rely on themselves shortly afterward.

1.2 On the treatment

As for health status of the patients after having brain injury, they needed intensive care from health care teams. The results of the study revealed three factors related to effective treatment as follows:

1) **The primary assistant is the other person.** Since the accident happened outside their residence, most of the patients received first aid from the passerbys who happened to witness the accident. Some relatives received the news immediately and had helped move the patients to the hospital, while some relatives learned of the accident after the patients were brought to the hospital. The wife of one

patient who learned of her husband's accident from the neighbor and arrived in time to help bring the patient to the hospital narrated that:

> "...friends from the factory told me (about the accident) ...he came to tell the doctor..."

Another case was the mother of the patient who was informed of her son's accident after he was already brought to the hospital. She said that:

> "...He (the patient) rode the motorcycle to pick up his father... His father (came from the province) arrived around 2 am... but he had (motorcycle) accident some where on Ram-Indra Rd. The passerby (the staff of the social welfare foundation who patroled the road) ...took him (the patient) to the hospital.."

Data obtained from the patients' record revealed that many had been brought to the hospital by the staff or volunteers from the social welfare foundations that usually patrol the road to help the people on the road.

2) **Having no idea of what's happening** After having been hit hard at the head during the accident, some patients still had consciousness, spoke consciously and had no apparent sign of injury. Many did not tell the family about the accident. Once the intracranial hematoma became bigger, then the symptom of increasing intracranial pressure was present. The patient's level of consciousness became worse, some vomited and finally lost their consciousness. Knowing nothing of the accident left the family with no idea about the cause of the illness. This happened to one case that the relative brought the patient to hospital after finding out that the patient had lost consciousness without knowing the history of this injury. The family caregiver related this case phenomenon that:

> "He (the patient) came home and said nothing, ate and went to bed... had vomited later on and only murmured some words when I asked. I thought he was drunk, so I left him sleep until morning. He did not wake up, so I let him go on sleeping. He still did not wake up. I was mad, so I ignored him until the other day only to find out that he was unconscious. We brought him to the hospital and learned afterward that his motorcycle was crashed before arriving home. He did not tell me of the incident.."

In the case of the patient who was diagnosed with mild brain injury, the physician usually observed them for a short period at the hospital. If no increasing intracrenial pressure was tracked, they would be discharged. The caregiver would have to observe for any neuro-abnormal sign that may likely occur. Lack of knowledge about the symptom of the brain injury was usually the cause that makes the patient or the caregiver overlook or unable to observe any minimal abnormal sign until it becomes critical. The story of the daughter-in-law of one patient reflected this phenomenon when she said that:

> "Mother had fallen down...she went to the hospital...(name of a government hospital)... The doctor (after examining her) said OK...and allowed her to come home...gave some medicine...(mother) had headache...took the medicine.. still thought everything was alright... (I) took her ...(because) she told me that she could not stand the pain anymore...She had severe headache..(she begs)...take me...if you leave me home for another night I will die...I (mother) know... take me..(to the hospital)..."

Another patient encountered similar episode. The patient's daughter stated that:

> "Mother fell down form the motorcycle...(I) took her to see doctor here...had been observed for 2 days...The doctor said nothing was severe. She could

> go back home. We were told to observe her symptom if any abnormal happened we were to bring her back to the hospital… Things seemed to be OK just the feeling of the wind blow out of her ear. That feeling lasted for several days. (Mother) went to see the doctor at the clinic (name of the clinic)… near the entrance of Lad Prow Road… He (doctor) told (mother) that she had Lom Takung (an ailment with symptoms of morning headache) and…also told her to hit the nail into the trunk of tree about 3 inches deep for three days at sundown and that feeling will fade away….Mother did as told on the first day around 6 pm….(she) hit a three-inch-nail into the tree in front of the house…hit until the nail disappeared… forgot to ask whether to hit one inch for three days or three inches for three days…That night mother (symptom) was down… so we took her to the hospital and had immediate surgery that night…"

The son of this patient gave further information that:

> "Mother had headache but she withheld it… before coming to the hospital she had severe headache…vomit after eating…"

3) Changes of care from one hospital to another. In general, the patient who had an accident would be brought to the nearest hospital, which could be a government or private hospital, a clinic or local hospital, either by those who witnessed the accident or the relatives. After receiving basic treatments from these hospitals, most patients were transferred to another hospital for several reasons. Some patients would be referred to another hospital to receive appropriate care according to the patients' need. Reasons were variedly told as follows:

a. Feeling that the doctor do nothing/cannot do anything. The brain-injured patients usually need complicate treatment, which is sometime beyond the capability or is not available in some hospitals. Therefore, in this study, some patients were transferred from a private hospital to a government hospital and some were moved from a local hospital that provided only minimal treatment to the hospital that provided tertiary care for proper care. The reason from the wife of one patient simply went this way:

> "...(we) first went to the hospital (provincial hospital) and the doctor told (us) that (the patient) had hemorrhage and recommended this hospital..."

Referral to a tertiary care hospital could provide better equipment and medicine to the patient than the primary or secondary care hospitals. However, the time spent during transfer and the distance between the two hospitals sometimes aggravate the injury. This case happened to one patient, as the family caregiver said that:

> "...at first he (the patient)... was still conscious...we took him in to the car and brought him to the hospital (local hospital) ... when arriving... the doctor came to check and told us that...it was about brain...and this hospital could not treat the brain-injured patient... no equipment... The doctor recommended (the caregiver) to take him (the patient) to Bangkok. He was brought again on the car...from the house to the hospital (name of the hospital)...from that hospital to this hospital, it took around 2-3 hours...when we arrived... he completely lost his consciousness..."

Effective diagnosis consumes time and requires complicate treatment process. The family and caregiver that do not understand the process may misunderstand that the physician did not attempt to save the patients. Wait and see is not the right treatment their loved ones deserve. Some family caregivers asked for referral to another hospital which they believed could provide better care to the patient. The mother of a young female patient said that:

> " We first brought (the patient) to see the doctor at… (the name of a local hospital)…The doctor told us to leave her there for observation… gave (the patient) intravenous fluid and did nothing. The next day my daughter was not better and seemed worse, so I told the doctor...move!… when (the patient) arrived here she was immediately brought to the surgery…"

b. Wanting to be at a trusted place. The past experience and impression forms the trust and confidence in care some hospital provide to the patients in the caregiver's mind. Health benefits from the office also affect the choice of the referral hospital. Most family caregivers would select the hospital that they believe could answer the patients' need although moving to another hospital cause difficulties such as increasing commuting time, longer distance and traveling expenditure between hospital and home. In this study, some family caregivers had to stop work and lost their daily income during that period. This patient who was the soldier requested to be transferred from the provincial hospital to Bhumibol Adulyadej Hospital for a nostalgic reason of his mother as follows:

> "The person who found him brought him to the hospital… and someone came to tell me that my son had motorcycle accident and right now had been brought to hospital… I followed that person… then moved him (the patient) here. We always came here for treatment…I want him to get medical treatment here… I gave his birth in this hospital…"

c. Having financial difficulties. The treatment cost and the entailed debts afterward are important factors that force the family caregiver to move the patient from a private hospital to a government hospital. This reason is concerned with the economic factor, which worsens the already bad situation of the family. The stories from the devoted mothers of the patients support this scenario. The first saids:

> " We (the relatives) brought him to ... hospital. We were told that he (the patient) had hemorrhage and needed immediate surgery... The next morning we were informed again that the patient had to undergo another surgery because of bleeding.... That was too much...only one night we spent several hundred of thousand...we told the doctor there that we wanted to move (the patient)... that morning we came here and had instant surgery..."

Another mother had different scenario from the previous one:

> "...on Friday evening (we) were there...... hospital and moved here. I knew this hospital but her (the patient) case was critical so she had to be brought to the nearest hospital first... be there first.... We needed to consult the doctor before transferring the patient. We could not just move her in the minutes... The doctor said that he knew and understood our needs. The doctor understood our financial problems and helped find the bed..."

The aforementioned findings reflected the social quality in terms of giving assistance to each other, knowledge and perception of the people, and the limitation of the health and medical service structures of the state that positively and negatively involve the caring process.

1.3 Hearing the bad news

This part of the tragedy began when the family caregivers received the news of the accident from a witness, concerned officers or another family member. These caregivers had different ways of receiving and responding to the news.

1) Terrible shock Receiving the unexpected news of the accident and the symptom of the patient and seeing how the patient endure the pain cause the relatives' terrible shock, misery, confusing, blurness, and makes them not knowing the right things to do. Some relatives who received the news of this accident after the patient had been brought to the hospital said that this incident was so sudden and unexpected. This frightened them and caused their heart to sink, made them confused and not knowing what to do. These feelings were similar to those of the relative who had witnessed the accident, as this husband described how he felt about his wife unfortunate accident:

> "I felt my heart lost…couldn't explain…didn't want this to happen…everything…wish this should not happen… confused…. cannot do anything..."

If this accident was the first time for the family, they became panic, terribly scared, and worried, as one patient's wife who had witnessed the changes while the patient was being transferred to the hospital had recalled:

> "… That time …my heart sunk…could do nothing…I wished I called my sister, mother but could……I didn't know what to say…scared about everything…I'd never seen this before…"

Similar feelings had occurred in the heart of another family caregiver. She confessed that.

> "…My heart was shaking…scared…no one in the family ever had this.."

The feeling of the family caregivers whose relative was in a critical situation went in the same direction. The feeling of another family caregiver who used to nurture the patient from childhood shared her feeling when first heard about the accident after the patient had been brought to the hospital that:

> "...When I heard of this accident (I) was lost could do nothing...didn't pack my clothes properly... just threw them (in the bag) and other relatives took me to the train station..."

The patients, who received severe injury, usually needed immediate brain surgery to save their lives. Upon knowing the situation, the relatives would encounter serious stress and high anxiety, as they perceived that brain injury was extremely dangerous and probably fatal. To undergo brain injury meant that the patient was in the most critical situation. They perceived that this was a life threatening period and the only chance of survival was the brain operation, which was also equally frightening. One family caregiver told the investigator how shocked she was upon hearing the diagnosis from the doctor. She said that:

> "...my heart was terribly sad...heard the doctor said that (the patient) needed surgery. I was numb.. Burst out my tear ...I was confused... The doctor insisted that (the patient) must had the surgery right away for it was very dangerous to leave it like that... I told the doctor...I must call my father and wait for him..."

This kind of feeling also occurred in the heart of one patient's wife. She frankly stated that:

> "..(I) thought it was not that serious ...seeing that (the patient) was under observation...but seeing ..(him) being moved to the surgery room...my heart sunk...brain surgery was serious...really serious...(I) saw him irritably moved about this morning..."

Such feelings occurred because most family caregivers perceived that brain surgery was a severe case. Seeing the patient in a critical condition caused confusion. In some cases, the family caregivers did not understand and have doubt when the information from the physician contradicted what they had seen through their eyes. They saw no signs of the severity from the physical appearance of the patients. Some of the family caregivers told the investigator that they were confused and did not understand when the physician said that the patients needed surgery. What the physician had said was contradicted to what they had seen from the patient as this brain injury happened within the patient's body. The following phases reflected the discrepancy of the perception of the symptom between the physician and the family caregiver:

> " When the doctor said (the patient) needed surgery…I asked to myself why? …. Because he (the patient) could still walk… (he) was not sick…just had the stitch from the wounded ..That was all we'd seen…"

2) Temporary loss of perception and communication ability. For the subjects in this study, the incidents brought the stress to the relatives who would often engage in different behaviors to release their fears. Some cried, with tears dripping, mourned, and were unaware of the surrounding, vaguely and unconsciously stareing around. Moreover, these stresses lowered the ability to receive information and communicate of many caregivers. They explained that they could not talk or relate the sequence of what had happened to the others while at the same time could not understand what the others had said to them. Some was fortunate enough to understand some of the information that had been relayed to them, while others had to rely on other person to communicate with the health care team. Besides, some needed assistance from other relatives to decide about the treatment and other practical activities. Examples of their responses are as follows:

> "…I was blurred…the people in the factory came to help…helped me talk with the doctor…I didn't want to know anything…"
>
> "…The nurse also told me ...but I couldn't remember what she had said…"
>
> "…Couldn't receive anything…talking with the doctor...I had to have someone with me…to help remember what the doctor had said…because I couldn't remember…"
>
> "…(I) also wanted to ask the doctors and the nurses but didn't know how...asked...sometime…(I) felt nervous…could listen…but later I was blurred…again…"
>
> "…(I) wanted to have someone to help guide…suggest what I should do…because I didn't know what to do really…(I) was really confused…"

3) **Facing the reality.** After the accident, most brain-injured patients need immediate diagnosis and treatment since the pathology and the severity of the brain injury limits the golden period that determines the survival and the reduction of the disability of the patients. Therefore, the family caregivers should be informed of the patients' symptoms and treatment plan as well as the possible outcomes in order to make the due decision within the short notice. Although most family caregivers are still under the terrible stress, anxiety, and are not ready to receive or decide whatsoever concerning the treatment, they have no choice but to participate in the decision making.

The findings at the present study revealed that brain injury had a great impact on the emotion and feeling of the family caregivers since this was instant and happened unexpectedly. They were frightened and blurred upon receiving that bad news. In some cases, this emotional disruption was crucial as this incident affected the perception and communication processes of the family caregivers.

2. The process of model development

The process of model development is described as follows:

Phase 1. Desperate need for reliance phase

This phase starts when the family caregivers suddenly and unexpectedly learn of the injury of the patient. They mostly feel "thok-jai" (heart sunk), "jai-hai" (heart lost), confused, and could do nothing. Seeing the worse of pain of their loved ones and the unfamiliar environment in the hospital together with the fatal situation of the patient aggravate the stress and anxiety among the family caregivers. Worse yet, they are informed of the treatment that is usually costly, and in some cases the complication of settling down the lawsuit which is also unusual to them increases their anxiety. Being shocked from the unfortunate event and having less ability to communicate and process information properly make family caregivers vulnerable to everything they should handle or provide to the patient.

Upon discussion with the key informants, health team, family caregivers, and the neuro-surgeon, the investigator realized that these family caregivers desperately needed the reliance. This reliance could be the angel who can help them help the patient, relieves their burden of the treatment cost, provides suggestion on the lawsuit, and finally offers them with spiritual support. Various needs emerged in this phase such as the need for helper, need for the financial support, need for lawsuit advisor, and need for spiritual support.

1. Need for the helper.

The need for the helper is a result of the family caregivers' perception and the meaning given to the brain injury in various situations as follows:

a) Near-to-death period. This feeling occurs when the family caregivers see the suffering the patient has been through, especially when seeing the patient lying unconscious with almost no movement and response to the environment, or couldn't communicate to the family members. The high-tech and sophisticated life-saving medical appliances such as respirator and several lines inserted to the patient's body is unusual and unfamiliar to the caregivers. In this study, many family caregivers saw these accessories as a death signal, which led them to loss of hope and they began mourning. This phenomenon was perceived as the "near-to-death period" of the brain injured patient among many family caregivers, as a mother of one male patient described:

> "...(I) called him.. he didn't answer...(I) felt hopeless... didn't know whether he would recover or not..."

Another caregiver said that:

> "... seeing her... at first I felt very sad...thought (she) never recovered... had terrible swollen face ...respirator...to give oxygen...many things...no chance to recover..."

b) Never be the same. Direct experience is an important attribute when this family caregiver assigns the meaning to the brain injury phenomenon. In this study, those who ever had a brain-injured relative explained that this injury was severe and could cause the patient's life. This perception led them to think that their loved one had a slim chance to survive. Even if the patient survived, he/she would be a handicaped and could not have a normal life as before. One caregiver shared her fear this way:

> "..(I) don't think he will survive…used to see my friend's boyfriend had brain surgery…he was different…like the abnormal…neurotic person… (I was) afraid…"

The above perception and meaning assigned by the family caregivers produced several emotional effects as follows:

1) Tamjai (Make do with the situation). This emotion mostly occurred in some family caregivers who believed in the religious doctrine which said "whatever will be, will be" or "fate." This feeling helped delight their hearts and gradually helped them to accept this fate, better or worse, die or survive with some handicap, etc, as one patient's mother sadly said:

> "..no matter what would he be…I have to make do…if he survived with some handicap… abnormal….(I) have to be satisfied with it…"

Another patient's wife gave similar sentiment:

> "….It has to be OK…whatever will be, will be…if that (death) is for him…."

2) (State of) Denial of the truth. On the contrary, some family caregivers could not *accept* this injury. This group of caregivers refused to see or avoided seeing the patient and didn't want to know anything of the situation for the following reasons.

> "...(I) was afraid to see...for fear that something would happen to her..."
>
> "...It's hard to accept...(I) would faint...feeling swaying...cannot accept...afraid of the telephone...afraid that the hospital will call to tell that something is happening to my son..."

3) Not wanting the patient to be like that. One family caregiver stated that she felt sympathy and wished this had not happenned to the patient, losing the functional and communication ability, as well as memory. Uncertainty of the situation aggravated the stress and anxiety among the caregivers. They were always found standing by the patient's bedside with their eye filled with tears, holding the patient's hand, mourning, or sometimes walking over to see other patients.

4) Pinning the hope on the physician's mercy. Some family caregivers put their hope on the physician whom they believed could help the patient as mothers of two patients strongly asserted that:

> "...Being in the hand of the doctor my son would survive..."
>
> "...without the doctor we had no one else to turn to......(I) wish the doctor gave her (the patient) the best care..."

2. Need for financial support. Medical expenses for the critical care and treatment are generally costly, as it requires high-tech equipment that renders the best and precision quality of diagnosis. Most of the family caregivers in this study had a moderate to low economic status. Their sources of income were uncertain; some were traders, agriculturists, or laborers work, who had limited income, so some had to get a loan from others with high interests. These factors created financial problems, especially among those caregivers whose patients were transferred from a private hospital. The wife of one patient desperately needed someone to help shouldering the medical costs. Both of them (the patient and the wife) were employees and had no supporting sources when the husband had the motorcycle accident. "I had financial problems," said the wife.

One family caregiver who was the daughter-in-law of the patient came from the family in which all members construction workers and had no social security insurance. They faced severe financial problems when the mother had the accident. The daughter-in-law expressed her problem:

> "...(I) was afraid that mother would not survive because we hardly had enough money...we earned in the morning and spent it at night...I thought hard... returned home to think and consulted with father and sister what best we could do..."

The relative and family of the patients struggled to find the money to pay for the medical cost, so they asked for financial support from other relatives and friends, got a loan, pawned some of their valuables in the prawn shop, or sold the land, etc. Several cases exemplified how they had tried their best to solve financial problems:

> "...She was an employee with no medical benefit...the money received from the insurance had already gone with the hospital expenses...this last bill was paid by the brothers and sisters...helping each other..."
>
> "...(I) didn't have money... this amount... I had to borrow with ten percent interest per month ..."

> "...My daughter asked me for the television... She took it to the prawn shop and get two thousand baht..."

> "... (I) wanted financial help...I spent more than hundreds of thousand already (for the private hospital)...no money...just sold the orchard (of the caregiver)...(I) had some money..(to pay for the medical cost)...."

3. Need for lawsuit advisor. As most of the patients got their injury from the traffic accident—motorcycle turning over or colliding with other cars, these cases required legal settlement to lay the claims and hospitalization costs according to the traffic law. The family caregivers needed a lawyer to act on their behalf and someone who can advise them on the lawsuit, as well as how to deal with the paper works according to the insurance laws. These steps were complicated and stressful for the mourning caregivers, especially among those who never experienced this event before. Many said accordingly:

> "...Could not think of things to be done... knew only that (I) had to go to the police. ..."

> "...Someone told me that this cost could be reimbursed from the insurance company...but..(I) didn't know how..."

4. Need for spiritual support. In this critical time of life, the family caregivers need spiritual support most. The data attained from the study revealed that the family caregivers had laid their hope upon the integration of the modern medical science and the Thai values and contexts. They trusted that modern medicine was the best treatment ever had for the brain injured patient while at the same time turning to superstitious beliefs. These spiritual supports filled up the hope that they sometimes didn't receive from the health care team. Data from the observation record revealed that many had increased their hope of the patients survival during the operation by asking their revered spirits to help protect the patient, or some turned to the household spirit. Some also laid a flower garland on the top of the bed near the patient's head as a symbol telling the spirit in that room to help protect the patient. Some gave the flowers to the Buddha image at the nurse station, or at the spirit house in front of the hospital, to ask for their blesses and protection. These sentences reflected the caregivers' emotions:

> "...Whoever told me of the good spirit in any places...I will go to tell those spirits... if (the patient) get well I will ordain him..."
>
> "...(I) only wish him to recover...but don't know how...seeing every sprit house (I) will pay respect to every spirit house.."

Doing those worships gave them higher confidance to face the reality, better or worse, and whatever may come.

Promotion of the family caregiver participation in care

The interaction process among the family caregiver, the patient and nursing staff begins as soon as the patient is admitted into the Neurosurgical Ward. The important role of the nurse is to provide care to the patients and family caregivers. These activities include: 1) saving life and preventing the patients' complications, 2) providing information to the family caregivers, 3) providing emotional and psycho-spiritual support, and 4) providing family caregivers the due consultation and access to facilitation as support resources. Nurse-aids would function in an assistive role to the nurse in the provision of patient activities as delegrated by the nurse. These included bathing and mataining patient hygine, maintaining their comfort, taking vital signs, feeding patients, ambulating patients, and dealing with equipment and supplies, etc.

1. Saving life and preventing the patients' complications. These activities are collaborative care between nurses and neurosurgeons to prevent the secondary brain injury. The physician would investigate and draw up a treatment plan that the nurse would follow with appropriate care. The due measures that could possibly be of help would be used. In this study, the situation went this way:

> "...When a new patient was admitted, the physicians and nurses collaborated in moving the patient to lie in a bed, positioning and relieving the patient's discomfort. Then, physicians and/or nurses checked the functionality of all external lines, which are connected to the patient. Then, nurses checked vital and neurological signs, gave medication and recorded in their chart. There would be a nurse-aid to help record vital signs and prevent accidents by restraining the patient and taking side rail up..."

To preserve the homeostatic brain and prevent secondary brain injury, the physician explains the pathophysiology, both primary and secondary brain injury, discusses and exchanges opinion with nurses about the information related to the treatment plans and reasons for each patient. This planned treatment would be passed to all concerned and the direction would be strictly followed in each shift. The due record concerning the developments of the patient must be properly recorded.

In this period, the nurse's role is to preserve the homeostatic brain and prevent secondary brain injury of the patient by maintaining normothermia and giving prophylactic convulsants, and setting the bed elevated at 30 degrees with the patient's head positioned in a neutral plane. Moreover, nurses have to maintain acid-base balance by assessing and controlling ventilation to maintain Pa $O_2 > 70$ mmHg and

$PaCO_2$ at 25-30 mmHg. If a patient retains the endotracheal tube or tracheostomy tube, she should have the airways suctioned every two hours and the amount of secretion assessed. If the patient requires mechanical ventilation or oxygen therapy as specified in the therapeutic plan, a major nursing participation is to monitor the ventilator and oxygen setting, as well as maintaining adequate fluid and electrolyte. Recording fluid intake-output is also essential to assess the fluid balance and prevent brain edema. Furthermore, the maintenance of systemic systolic arterial blood pressure between 100 and 160 mmHg is important in order to prevent systemic hypotension. The steroid therapy would be given in order to decrease brain edema as well as other medications to prevent stress ulcer. Vital signs and neurological signs should be monitored every hour or more in order to early detect abnormal signs of increased ICP. If there are vital signs or neurological sign changes, immediate report to the physician is required.

Because most patients generally lose their consciousness and could hardly care for themselves, several lines insertions such as endotrachial tube, surgical drains, intravenous fluid, and Foley catheter would be needed to preserve life. To prevent complications, nurses should reposition the patient every 2 hours or more, and assess the characteristics of the skin and the tissues for abnormalities including blisters, hyperemia, rashes, redness from high and prolong pressure. Catheter and joint coming from a patient should be checked to prevent leakage and contamination.

Special attention to alleviate the patient's discomfort both from physical and psychological conditions should be observed. The due information should always be provided concerning the treatment in observance of the human right of the patient and the family caregivers.

2. Providing information to family caregiver. The initial goal of giving information to the caregivers and their family is to reduce their anxieties and fears. It would be a physician's or nurse's responsibility to give, without reservation, information related to the patient's conditions, the therapeutic plan, the results of previous treatment, and the prognosis. A physician would propose choices of therapy, but the final decision would come from the family members or caregivers.

In addition, nurses should provide the information related to the hospital, the regulations and the required performance during admission in the hospital as well as give the guideline book. Additionally, nurses should explain to the family caregiver the entire nursing care plan, its outcome and the patient's right. The communication between nurses and family members would be both nonverbal and verbal communication in the friendly manner to relieve fear and stress from the family caregiver. Feedback opportunity for the caregivers to ask some questions should be provided. Lastly, caring, empathy and concerns should be expressed to show the nurse's understanding of their suffering and vulnerability in time of crisis. In some cases, family caregiver may need other family members to participate in discussion and decision making about the treatment method; therefore, other family members should be invited to join in the decision making. Data from the present study revealed that oftentimes nurses and a physician had to repeat what they had said to the caregivers as they were still under depression or anxiety that undermined their thinking and communication ability.

Precaution. The customized language such as medical terms given to family caregivers in the confounding and confusing state of crisis not only impaired perception but also increased stress, confusion and anxiety of the caregivers. For example, a family caregiver told the investigator and nurses that:

> "A doctor said obvious words... enhanced my concerns and anxiety. Will he be eternally sleep (as seen)? Is it dangerous? I do not dare to ask."

Therefore, giving information related to patient's condition should be simple and the medical terms must be avoided. In addition, the family caregivers should be encouraged to ask questions if confusion has clearly been observed. Moreover, nurses should be able to observe the behavioral clues of anxiety including facial expression and emotion.

Investigation of information giving Unfortunately, it was found that three family caregivers did not receive any information related to patients and other information from the nurses or the doctors. To bridge this gap, the checklist of the due information should be prepared and attached to the patient's chart. The item of information that has been given to the patient should be recorded and endorsed by the provider. The nurse on duty of each shift must see to it that each item of information has been provided to the family caregiver within 24 hours after admission to the unit.

3. Emotional and psycho-spiritual support for the family caregivers. There are many nursing interventions to emotionally and spiritually support the family caregiver, such as the therapeutic relationship. Polite introduction, putting a name tag of the in-charge nurse in front of the room, caring expression and sensitivity to psychological conditions and anxiety of family caregivers are the supports that could be provided by the nurses. This support entails empathic attitude and attentive listening to the repeated story that could encourage the family caregiver to share their feelings. Giving consultation assists family caregivers to understand and face the situation. Moreover, nurses should encourage family caregivers to develop their problem-solving skills by talking with other caregivers, or performing the religious activity. Furthermore, nurses should accept the combination of therapy between modern medicine and traditional beliefs, which causes no negative effect on health status of the patients such as facilitating the family caregivers in paying respect to the holy spirits.

4. Consulting and facilitating family caregivers about the cooperation as support resources. Nurses should advise the family caregiver about the process in solving the problematic issues, facilitate the significant document and coordinate with the staff of support resources. Moreover, the nurse should arrange with the all unit concerned for the proper procedures and the required credentials that the family caregivers have to bring along before contacting the units. Office hours and specific regulations pertaining to the specific unit must be clearly provided in order to prevent any delay or confusion among the family caregivers.

Factors influencing family caregivers' abilities

Several factors have influenced the caregivers' abilities during the dependent period.

1) Trust and reliability. The trust occurs in family caregivers when they believe that the health personnel could help their loved one. Their beliefs come from witnessing the collaborative management among nursing staff and physicians in trying to save the patient's life. The routine cares, the concerns, the assistance for any emergency problems and the continuous information giving from physicians and nurses comfort the caregivers' mind and gradually change to trust. Furthermore, the therapeutic relationship between nurses and family caregivers increase the trusting feeling in the family caregivers. Communicating in the comfortable atmosphere assists the family caregivers to enhance their problem-solving skills. This trust consequently relieves the anxiety of the family caregivers and finally makes them ready to join the health care team in caring for the patients, as one family caregiver had voiced:

> "...as I saw them (doctors and nurses), they provided good care for my child..."

2) **Caring and compassion of the nurses.** The family caregivers may see that the compassion of the nurse reflects in the form of advice, explanation, follow-up of the progress of problem solving, assistance with the legal process. Handling those troublesome problems was difficult and depressing as some narrated that: "nurse always inquired of my needs.... do you do this or do you do that?...".

Furthermore, some family caregivers needed the financial support for the therapy, as a family caregiver stated:

> "the nurse in the morning shift suggested that I bring the insurance document from the head of the village. She regularly asked the questions to see the progress of the process, the barriers and the needed assistance."

3) **Sharing information among family members and helping each other.** One of the important factors which relieve the family caregivers' suffering and anxiety is sharing and reviving information from nurses and physicians. Physicians

and nurses give information regarding the therapeutic effort, the nursing intervention, the introductory advice related to hospital facilities, rules, regulations and proper performance. Moreover, family members could participate in decision making to solve problems. They also support and assist in proceeding some process. For example, a patient was a 14 -year-old boy who had motor vehicle accidents. The physician diagnosed left tempero-parietal epidural hematoma and the patient had received immediate surgery—craniotomy—to remove blood clot. After having surgery, he was transferred to the Neurosurgical Ward. Observation of the mother's behaviors revealed that she was sitting besides his son's bed with **mournful** face. Receiving the information related to the patient and the advice from other family members, the caregivers sat, watched the nurse and did not say or ask anything. Then, she walked and looked at other patients and came back to sit on the same chair until returning home with her relatives in the evening. The next morning, she brilliantly came by to say hello to the same nurse. The advice from her relatives clarified what she had heard but never understood before. She clearly understood how the symptoms and treatment of the patient had been so far:

> "She (the aunt of the patient) told me that this nurse was very good, tried to talk and give information related to the patient 's symptoms. Whatever doctors and nurses had prescribed for him, this nurse could explain it very well.'

Another family caregiver, a wife of a patient, reported that the family members, particularly the patient's mother, participated in the provision of information related to the patient's illness, symptoms, therapy and other problems. The patient's mother gave several assistance, support, encouragement, sympathy and proceeding in several issues such as the therapeutic payment.

The outcome of the first phase.

1. All patients had survived without contracting secondary brain injury or any complications. The outcomes could be classified according to the severity of the symptom as follows:

All severe brain-injured patients needed the whole compensatory care. Their Modified Disability Rating Scale was from 10 to 17 points.

Five moderate brain injured patients were alert and could follow the command. Some patients had regained their composers well, whereas others were still confused. Their Modified Disability Rating Scale ranged from 14 to 21 points. Some patients needed the whole compensatory nursing care, whereas others demanded partly compensatory care.

The patients with mild brain injury needed short care and rehabilitation. They could spontaneously open their eyes or open their eyes following the command. However, two patients had confusion. All patients had to depend upon the other persons for their daily living activity. Their Modified Disability Rating Scale ranged from 20 to 33 points.

2. The family caregivers relieved their anxiety and could proceed with several important issues. Seven family caregivers filed a complaint for the due compensation from the insurance institute, while five family caregivers paid for the therapy. Nurses were the people who could solve the problems related to essential medication and medical equipment. Then, the family caregivers would be paid for the damage. Another family caregiver waited for the result of the insurance document being reviewed by the insurance company. Six family caregivers filed the lawsuit and won the case. However, three caregivers were not eligible to lay the claims because their accident contract had expired. Nurses also advised and contacted social workers for financial support. The family caregivers that could process several issues mostly received advice and followed up results from the nurses. They also had other relatives to participate in receiving and giving assistance.

All family caregivers were willing to participate in providing care to the patients. Most family caregivers (15 persons) eagerly expressed their will to take care of the patients since the first day of admission. Other seven family caregivers came to provide care on the second and third day after their family members or the patient's friends gave care at the first day for various reasons. Two persons had to handle the claims from the insurance company, two tried to cope and relieve their anxiety, and three persons had to travel from other provinces. Although having a mournful face, eye filled with tears while conversing with the nurse, they wanted to stay nearby help the patients' company. Allowing family caregivers to stay and care for the patients was the direct response to the family caregivers' spiritual needs.

Phase 2. Ready for participation

This phase began when the family caregiver felt that they should be responsible for providing assistance to the brain injured patients. The need to participate in the patient care occurred when the heath status of the brain-injured patient required close and intensive care and continuing rehabilitation. Several reasons were cited such as love and care, wanting to be close to each other because living together for a long time, understanding each other, duty and responsibility and paying a tribute to the goodness of the patient.

1. Love and care. This reason came from the caregivers who were family member or siblings of the patient such as mother and son, brother, husband or wife. This bond kept the family caregivers close to the patient for fear that something might happen to their beloved. These family caregivers did not want to miss any information concerning the symptoms and their changes, considering the following reasons:

> "...Bonding between mother and son...he is my only son...worried a lot...want to be with him...I am willing to do this...(for) my son..."

> " ... Husband and wife...we have to take good care of each other...worried about him...wish to care for him..."

2. Close to each other because living together for a long time. Some family caregivers stated that because of the strong bond between each other make them care for the patient. Most of the family caregiver who gave this reason were the patients' wives who had been together with the patients for a long time:

> "...Relationship...we had been together for 20 years from nothing until we built the house... the land...we fought the hardship together..."

3. Understanding each other. This group of family caregivers decided to care for the patient because of the previous close relationship between them and the patients. They knew exactly what the patients wanted or needed better than the others, so they believed that they would be the best caregiver to the patient, as some had said:

> "...He told me that the nurse carelessly gave him the care...he didn't like it...(I) knew him better...know his needs..."

4. **Duty and responsibility.** Some of the family members became the caregivers because other members were not available. Data from the study revealed that the problems that prevented them from helping were age, health status or work. There was only one family caregiver whose age, health status, and present job was conducive to be the caregiver. Being the eldest son forced some caregivers to take this burden. In some cases, the relative had to get involved because the patient's family was the single family that had only the husband, wife and a young son. The relative had to step in this situation:

> "…I saw that the patient had no one to care for him… every one had their own commitments…they had to travel to different places…"
>
> "…It is my duty…there were three of us in the family …I had to come...it is responsibility."

5. **Pay a tribute to the goodness of the patient.** One became the family caregiver because she was aware of the good things that the patient used to give her "…Because she was so good to me...want to do something for her…"

As far as the responsibility of the family caregiver was concerned, three groups of family caregivers were identified: 1) sole primary caregiver; 2) one primary caregiver with one to three secondary caregivers; and 3) two primary caregivers with no secondary caregiver. These groups had different characteristics as follows:

1) **Being sole primary caregiver.** This sole primary caregiver type provided cares throughout the hospitalization period and after discharge without any assistance. This type of caregiver had the least limitation among the family members. They were the transient worker, housewives or the person who could afford to

temporarily leave their jobs. Those who had limitation cited the following reasons: other family members were occupied with their job, lived far away from the hospital, and had travelling difficulty. These factor left the caregiver with a slim chance for a substitute to attend to the patient's need. Some family caregiver came from the single family that its number was limited to only husband and wife or father, mother and young son at the schooling age. When one in the family had an accident, the rest had to take full responsibility with no choices.

2) **Being one primary caregiver with one to three secondary caregivers.** In this type of family caregiver, the primary caregiver would be the best who knew and could attend to the patients' need. This primary caregiver usually had closer contact and provided direct care better than the others throughout the hospitalization and continued this care at home. Other family member sometime took turns as primary caregivers or acted as secondary caregivers in some activities. This assistance could come in three forms as follows.

a. Once-in-a-while assistance. The secondary caregivers sometime replaced them as a primary caregiver when the primary caregiver was not available.

b. Scheduled help. The secondary caregiver would come to replace the primary caregiver at a certain time according to their timetable at their convenience: morning, noon, or evening. This was intended to alleviate the burden of the primary caregiver. The primary caregiver could escape from the scene for a certain period to attend to their household chores as in the case of the housewife.

c. Rotating care. This type of care was the take-turn format. This type happened in the family in which each member had to work and could not have a long leave. They were government officers, employees of the state enterprise; or employees of a private organization. Although certain family member was authorized to make any decision concerning the care provided to the patients, every one would help share the responsibility. They would try to rotate their work to fit with everyone's timetable. At the commencing phase, the caregiver mostly dealt with solving immediate problems. These caregivers had to adjust the treatment plan during the first one to two weeks. The plan could be revised if appropriate to find the best strategy.

3) Two primary caregivers with no secondary caregiver type. The characteristics of this type meant having two primary caregivers. They should understand the problems and needs of the patient and had enough free time to attend to them. This type of care required participation from all concerned. Most of these caregivers were parents or relatives from the province. In this study, there was a family that had only one or two sons. In the only son case, the patient was the only hope of the family. Other reasons that prevented the participation of some other family members were: living in the province or far away for the hospital, having difficulty travelling, and being unable to refrain from the present job. They usually were traders and agriculturists.

Meaning of family participation.

Understanding of the meaning of family participation varied according to the perception and need to get involved of the family caregivers. For them, family participation was seen as that of doing everything that the patients could not do and did all the best they could to speed up the recovery of the patients. The duties ranged from attending to the daily activities such as cleaning the body, changing of cloth, cleaning after disposing of the waste, feeding, turning the patient's body, supporting the rising up of the body, giving massage, monitoring of any possible harm or accident that may occur, reporting any changing signs and symptoms to the health care team, and providing stimuli to the patient by touching the patients and talking to them to improve the patients' cognitive ability. One family caregiver described that:

> "..... I help by attending to all the patients' need as much as I can..... Cleaning the body, feeding, taking the patient to the sitting room...."
>
> ".... Cleaning him...anything (I) can do (I) will do for him..."
>
> "...Want to do everything I can to help him recover soon...massage his legs, knees, everything to stimulate him...call him to let him know...."

Many family caregivers believed that the patients needed warm attention. Seeing no one around made the patients feel deserted and unwanted. The patients desperately needed moral support, as this was an important factor that could facilitate the fast tracking recovery. Therefore, providing care would be interpreted as a way of providing moral support as well. Talking, holding or patting the hand, giving massage, etc. were ways to communicate with the patient how much the family caregivers cared for them, and wanted to be with them with whole-hearted support all the times. The data obtained from the interviews reflected this implication:

> "...Support him... moral support is important...."
>
> "...During the paralyzing period, he cannot help himself.....I will help support him up and down, hold his hands, and be with him...."

The family caregivers further explained that family participation was coordination or a medium between the patient and the health care team, to convey the message of the symptoms and needs of the patients as the caregivers were more or less acquainted with the patients than the health care team. Regarding the health care team as strangers discouraged the patients from freely expressing their true feelings and needs:

> " ...She will wait until she cannot stand the pain...I will have to tell..."
>
> "....the patient is not so depressed while with us...sometime she is afraid of the nurse...seldom says a thing...if I speak ...stimulate...to tell ....she (the patient)...must tell the nurse (of her needs or feelings)....she still doesn't...."

Besides tending to the physical need and giving moral support, "do every thing that can be done," may be interpreted as "what the nurses had asked, the family caregiver will do everything as asked". This reflected the belief of the family caregiver that following the nurse's suggestions would be the better way for the patients:

"...They (the nurse) have studied ... they know more than us...," was the best explanation that penetrated to the root of this obedience. This explanation also held true for the physician. The family caregiver also believed that the physician was knowledgeable, had expertise and held full authority to execute any decision concerning the diagnosis and treatment. Therefore, choices for treatment would be "up to the doctor." The following statements best supported this conclusion:

> "....if the doctor sees fit, I also agree because I have no idea at all about this matter..."

> "...the doctor has studied the matters... his principle and our principle are different..."
>
> "...the doctor and the nurse have passed through the best study and training...to be against their decisions would be improper...(we must) honor them...honoring their degree...(they) know more than us...I think he is the doctor, he must know (better)...."

Expectation of participation in the patient care

The family caregivers used the word "recover" to explain what they hoped about the health status of the patients as an outcome of the involvement in the patient care. However, there was no clear explanation of what "recover" was like, or how and when it would occur. Some had said that recovery meant the patient's conditions had been returned to normal as it was before the accident; others accepted that recovery might not mean totally full recovery. The handicap may remain for some time and now, but this handicap could still allow the patients to perform many kinds of activities. For some other family caregivers, this recovery meant "partial recovery only." After discharge, the patient still needed further care at home for quite sometime. The definition of "recovery" may be stemmed from the direct and previous experiences, past experiences, and the experiences gained while in the hospital.

Some family caregivers also needed the patients to sense how they felt for them. One family caregiver believed that the care given could be a medium to communicate her feeling to the patient:

> "...Help him... care for him... makes me happy...good to have a chance to care (for him) ...I wish him know that I love him..."

On the other hand, some family caregivers saw the family participation in the hospital as a preparation for the care at home:

> "…. (This) helps me know him…know how his symptom fares. When we go home we know how to care for him. Sometimes, if we don't know a cue…we may be upset. Once we know we are prepared, at home, we must take care of him…on and on…how he will survive…"

Imitating what the nurse had done for the patient gave the family caregiver an idea and knowledge on how to provide the same care to the patient at home. The following statement supported the notion of family caregivers' effort to learn.

> "…Seeing the nurse tending to him (the patient)…I wanted to help…because when we go home I can do the same thing correctly…"

Many family caregivers expected that taking part in patient care could accelerate the process of information reception. Direct experiences and correct information gained from the health care team could facilitate the learning process. However, the data obtained from the study revealed that the family caregiver wished that the health care team should pay more attention to them, too. The health care team should also ask about their problems and needs as caregivers. To participate in the care process was seen as an attempt to lessen the burden of the permanent health care team due to the fact that a government hospital usually had an imbalance ratio between the number of the patients and the number of the health care team members.

Promotion of family caregivers' participation in care

1. Patient rehabilitation and prevention of complications These activities are the collaborative care between physicians, nurses, psychiatrists and nutritionists. The physician would examine and visit the patient regularly every day to investigate the progression and abnormal signs as well as to plan the therapy. These activities were intended to rehabilitate the patients and to free them from complications, disabilities and morbidity. The physician diagnosed and planned the treatment according to the information from physical examination, laboratory test, chest roentgenology, nurses' reports concerning patient's progress and discussion with nurses about the therapeutic plans and other related problems. Moreover, psychiatrists would also be invited to join in the diagnosis discussion, therapeutic plans and physical therapy. The physician's regular examination and visit would enhance the family caregivers' encouragement and confidence in giving care to the patients.

The nursing practice to rehabilitate and prevent patients' complications was base on three variations in the nursing system of Orem's nursing model. It included the wholly compensatory, partly compensatory and supportive–educative nursing systems. The first system is intended to provide care for unconscious patients and/or those unable to move about in order to accomplish patient's therapeutic self-care. It includes the ventilator management to maintain adequate tissue oxygenation and prevent respiratory infection. In addition, its function is also to maintain adequate fluid and electrolyte, nutritional support, personal hygiene, elimination care system and prevent urinary tract infection. Preventive measures for pulmonary complications and pressure sore is repositioning an every 2 hours. In addition, they have to manage sufficient sleep and rest, perform active exercise to prevent muscle atrophy and stiffed joints, and record vital signs and neurological signs to monitor the abnormality for immediate management. In-patients who are conscious and can perform partial self-assistance, nurses would give partly compensatory care. This nursing care depends upon the individual patient's care requisite and abilities. In addition, nurses would cooperate with psychiatrists to facilitate for patients' physical therapy. They also collaborate with nutritionists in nutrition management to prepare sufficient nutrient and energy to meet the patient's physical requirements.

2. Providing information. Information concerning treatments or interventions, such as invasive lines and the technological equipment, its characteristics and usefulness, especially in a critically injured patient and the postoperative patients has to be provided to the family caregiver. Such information would help the family caregivers to see the reasons and the needs of using several technological resuscitated equipment such as endotracheal tube, mechanical ventilation, tube drains, nasogastric tube, intravenous fluid and Foley catheter.

They also have to assess and educate family caregivers regarding providing care for all patients either able or unable to carry out activities. The simple activities include general hygiene, eliminative process and excrements, observation and report about the patients' abnormalities, and the participation in the decision-making about the treatment allowed for the family caregivers. The activities that require technical knowledge and skills would not be off limited to the family caregivers. However, they would be of great help to report about the abnormality of this equipment such as prolonged or shorter respiratory sounds, the sounding alarm, the changing of body's color fluid secretion and the increasing amount of content to the staff on duty.

Precaution The findings revealed that some family caregivers unintentionally performed some activities producing harm to patients because they had observed such action from the nurse. For instance, they adjusted the rate of intravenous fluid when the fluid did not flow, or flew more slowly or rapidly than before. They also reset the ventilator's alarm to silence without detecting the cause of that alarm. Therefore, nurses should explain to the family caregivers about these activities and emphasize the patients' danger from such activities.

The physician should also give the patients' information about signs and symptoms, treatment plan, previous outcomes of treatment and the prognosis regularly and continuously to enhance the family caregivers' courage and confidence in caring for the patients. Moreover, some family caregivers asked about some questionable issues as well.

3. Mutual goal setting and writing care plan. After assessing the capacity and the readiness of the family caregivers, nurses would advise the family caregivers about the therapeutic plan and how to assist them. They also ask for the family caregivers' opinion and encourage them to propose their views and requisites in every issue. They would prepare to listen and assist the family caregivers and clarify that the participation in care was the collaborative care among nurses, physicians and family caregivers. The family caregivers would be informed of their authorized power to engage in activities as much as they could. The caregivers should also be informed of the in-charge nurse responsibility as well as the other on duty nurses to provide help and care for each in-patient. Family caregivers would collaborate with nurses in setting goals and suggesting the activities to achieve their set goal to nurses. Nurses would consider the appropriateness of an activity to the patient's conditions. Moreover, family caregivers should be allowed to express their needs and expectations to participate in caring for the patients to the nurses.

4. Teaching and skill training for family caregivers. The teaching and skill training are important nursing actions in preparing the family caregivers. Nurses would emphasize the caring activities, which usually are the family caregivers' problems and essential to caring for the patients. The key concept of teaching is the nurses' strategies to produce the family caregivers' feeling that the participation in caring activities is not difficult but necessary for the patients. Knowing the profile of the family caregivers would be of great help to maximize the teaching effectiveness.

Initialy, nurses would teach and train the family caregivers about general hygiene care, the physiological and psychological needs of the patients. They should start with simple activities such as bathing, shampooing, stripping, and managing bowel and bladder elimination. Then they would teach the more complex activities such as changing position, the enteral feeding via a nasogastric tube, clapping patients' back and chest (to eliminate secretion), the mobility as well as proper arm and leg exercise. Moreover, they should teach the caregivers about the abnormal symptoms which should be recognized and reported to the nurses and physicians for immediate assistance.

Demonstration is the most used method to educate the caregivers. Family caregivers require practice in every step of action to develop their skills;

therefore the teaching plan must emphasize the important aspect of such action. For example, for enteral feeding, the important actions are positioning, suction prior to feeding and aspirating the nasogastric tube prior to feeding. In caring for patients retaining Foley catheter, the significant caring is the actions to prevent infections including cleaning the genital area, transferring the urinary bag, keeping the catheter free of kinks and maintaining the closed system. Moreover, teaching about rehabilitation and prevention of patient's complications should be emphasized, especially the benefits of these actions and the severity of those complications. Moreover, they provide materials regarding patients' rehabilitation and abnormal symptoms which should be observed including headache, vomiting, decrease in level of consciousness and motor power, focal or partial seizures and generalized seizures. These actions require the experts from the health care team to practice the muscle and joint exercise or chest physiotherapy. Therefore, nurses should coordinate with physiotherapists to train the family caregivers these skills.

Furthermore, nurses should develop caring capabilities of the family caregivers with enthusiastic expression, teaching and concerning about caregivers' feelings. They should also admire the family caregivers for the successful actions and cite them example to the other caregivers as reinforcement. In addition, the supportive environment and atmosphere such as cleaning the ward and toilets, preparing the room for caregivers' rest and eating should also be provided to increase the participation of the relatives of the patients.

However, during the learning and practicing sessions. In this study some family caregivers began to observe the practice of nurses and other caregivers, realized those and tried them out with some mistakes. Other family caregivers would combine the previous experience with the assistance from supportive educative systems provided by nurses. This system provided information and knowledge as well as developed the significant caring skills. As a result, family caregivers developed the learning experiences as these family caregivers shared their insights as follows:

> "Looking at the actions of nurses and memorize them."
>
> "I used to do bathing. Don't tell me I know because I do it. They (nurses) have told me and taught me, then I could do it all… Yet, this is different. They use the equipment but I am a novice.'
>
> " There used to be a nurse and a nurse-aid who gave introduction and suggestion on what to do. However, I don't know how to put on the clothes and change the linen.'
>
> "In general, I will help turning him. They (nurses) demonstrated that and let me do it."

5. Collaborative evaluation. Nurses and the family caregivers mutually evaluated the effectiveness of the learning and analyzed the factors affecting caregiving and resolved to appropriate solution. Data revealed that two family caregivers did not attend the training, so they had to resort to their previous experiences. One reason was related to the patient's condition. A patient came to the hospital because of headache after having a motor vehicle accident. He had good consciousness, could perform his self-care and had no external abnormalities or impaired body functions. As a result, nurses who had to care for several patients at the same time would give their direct care to critical or unable to manage self-care patients. The other reason was related to the relatives. Another person had three family caregivers that were government officers. They had to intermittently stop working to maintain the daily care. As a result, they could not attend teaching and training sessions. Nurses and the family caregivers analyzed these problems and came up with sound resolution. In the first case, nurses taught and trained the extra skills which the family caregivers were likely required. In the latter group, after assessing each family caregiver about the knowledge, experiences and the caregiving capabilities, nurses cooperated in the planning of class schedule to provide the required information, which each family caregiver required to be taught and trained. Then, they let the caregivers transfer the information and skill among them.

Factors influencing the family caregivers' abilities

1) Previous experience in caregiving. The findings revealed that the effective measure in preparing the family caregiver to care for the patients was the teaching and practicing of skills such as bathing, turning, muscle and extremity exercise that the family caregivers should understand and follow. The reinforced factors were the previous caring experience, the learning by observation, and questions and trials whether right or wrong. Moreover, they received the assistance and support related to information, knowledge and steps of development skills from nurses. Thus, they could understand and had courage to do so, as one caregiver reported that:

> "…Everyone does the bathing… needs not be told… I know because I used to do it. The nurses had told me before. They assisted and taught, then, I could do all. Yet, this was different. They used all technological equipment. I had only my hands."

However, a family caregiver that did not have previous caregiving experience reported that:

> "On the first day, I walked away ....intentionally... But I've never done it, sometime, I could not accept it. First, fear... having a hard time..."

In such cases, nurses would perform wholly nursing care until those family caregivers were ready to learn and practice. Then, nurses would explain, train step-by-step, assist and support the family caregivers along the process. Admiration and exemplification were given as the reinforcement to those who could successfully follow the instruction.

2) **Sharing information among family members and helping each other.** The participation of family members to learn of the patient's injury, therapeutic plan and care with the family caregivers alleviate the burden and help solve the problems to the family caregivers. As a result, the family caregivers are encouraged and do not feel lonesome. The family also cooperate to share the sufferings and assist the family caregivers. In this study, 17 family caregivers had participated in the process. In one case, a 45-year-old female caregiver who was the eighth daughter of nine siblings became a caregiver because she was a vendor, the youngest and single, unemployed and could stop working, while other siblings were not available as they were government officers, married and had their own family. Furthermore, she was healthier than the other elder sisters. However, they would join in the processes, performing decision making, solving problems and learning to care so as to be able to substitute for her sometimes.

3) **Hope.** This feeling encourage the family caregiver to care for the patient. The findings revealed that the family caregivers hoped they could join in many activities as possible. Furthermore, the perceived information, the responsive

symptoms of head injury patron that the family caregivers could observe and/or the patient's wake up encouraged and equipped the caregivers with an ability to care for the patients. Aware that the recovering for this type of patients took time and a chance to return to normal was less likely, seeing the patient regained some responses and/or wake up delighted the caregivers, as one said with a cheerful face that "after the surgery…. (patient) couldn't talk…now… very glad."

4) **Reflection.** This process is a strategy used to enhance the family caregivers' thinking power and allows them to freely decide. These family caregivers would be encouraged to analyze the problems and find appropriate solutions. Their choices of action then would be honored. The practices and evaluation of the outcome would be mutually executed between the nurses and the family caregivers.

The outcomes of the second phase

1. Disappearence of life-threatening signs and symptoms of patients. Among the severe brain injured patients, three still breathed via an endotrachial tube, and the other two had the mechanical ventilator. Four patients regained motor response to localized pain. A patient could respond in general, whereas the other one could follow the command. However, all patients could not perform self-care and still received the wholly compensatory nursing care. Their Modified Disability Rating Scale scores ranged from 10 to 20 points

In moderate brain injured patients, 6 patients regained some orientation to time, places, and space and could follow easy command or confusedly talk. Some could properly communicate, but some could not. A female patient had retained Foley catheter because she could not void by herself. Most patients could learn to perform self-care for the daily living activity, nevertheless, they still needed assistance. Their Modified Disability Rating Scale ranged form 21 to 26 points.

All mild brain injured patients had increased orientation to place, time and person and could follow command, but three patients retained a little confusion. Their vital signs did not change to abnormality. They had no complication with Modified Disability Rating Scale scores ranging from 26 to 33 points.

2. The family caregivers' capability in patient care. Data revealed that most of the family caregivers of the severe and moderate brain-injured patients had previously experienced caring for patients from previous admission and some from child rearing. Therefore, nurses could prepare for the full-scale training activities. All standard caring practices had been trained and practiced, and information related to caring was also provided. The training goals were achieved and the family caregivers could perform the cares trained. In the family caregivers of the mild brain injured patients, these family caregivers spent one to two days on the orientation because all of them had previous experiences and the patients rapidly recovered.

Phase 3. Sharing of care

This phase begun when the family caregivers participated in the caring process. Activities at this period were usually simple and not complicated activities. These activities such as cleaning the face, fanning, massaging to make the patients feel more comfortable, reflected the love, care, and attention that the family had for the patients. To prevent the patients from unconsciously hurting themselves, the caregiver could hold the hand of the patient or using the voice to caution the patients if they moved, shook, or tried to remove any tubes. Experiences gained from training, on site observation, and appropriate information received increased the care ability of the family caregivers. Realizing the benefits of the recovery process increased the confidence and understanding that caring was not as complicated as it seemed. Gradually, the family caregivers could gain more experiences and could successfully participate in the caring process.

In this study, family caregivers had to look after brain injured patients whose severity could be devide into three levels: mild, moderate, and severe. The results revealed that the phenomena in the third phase were different as follows:

As for the mild brain injured patients, most activities which family caregivers could achieve to serve the therapeutic needs of the patients were simple and accustomed to their previous experiences. The learning and training they underwent added skills to the family caregivers and enhanced confidence in caregiving. Moreover, rapid recovery of most patients including improved level of consciousness after the first and second postoperative or therapeutic days, ability to communicate with family members and increased obvious response to environment produced hope and encouragement to caregivers. As family caregivers could perceive the improved conditions of the patients and received confirmed information from health care teams, family caregivers were glad, had hope and were assured to continue their caregiving. For example, a family caregiver said:

> "very glad ....as seeing the patient really improved... glad...seeing he sits ...could talk...and turn the body...."

Regarding the moderate brain injured patients, the phenomena began when family caregivers performed the wholly/partially compensatory caring. The general health status of patients obviously improved. The improvement increased hope and encouragement for the caregivers. This period was tough for the family caregivers, as great patience was required from them to endure the patients' emotional and behavioral disturbances. Some patients had weak extremities so that the family caregivers tried to find the strategy to increase the level of improvement.

Attending to the patients in their daily living activities as well as training them to perform self-care activities was a difficult job which required a lot of will and energy. Moreover, they had to protect the patients from danger, which would occur with confused and hyperkinetic patients who were restless, or tried to cross the bed. Some patients often called their family caregivers to reposition them and massage their extremities. Some patients also did not allow their family caregivers to be out of sight, but to be at the bedside at all time. Thus, this caring phase left the family caregivers exhausted. Nevertheless, the family caregivers entertained positive hope that their assistance would be of great help to reclaim the patients' health and recovery.

As regards the severe brain injured patients, since the family caregivers took part in caring for the severe brain injured patients, they generally spent their time with the unconscious patients who had little response to any stimuli and required prolonged and complicated care until the patients recovered. This caring process produced several impacts on family caregivers as follows:

1) **Depression.** Many family caregivers had concertedly agreed that providing care to the brain–injured patients put heavy stress upon them, seeing the

unpleasant symptom, enduring the suspicious mind of how big the chance for the patient to completely survive with no handicap left was. Seeing that the patients could not help themselves was also depressing. Uncertainty of how the future would unfold made the family caregivers severely depressed. For example, the mother of a patient cried when stating that.

> "..no hope...(I) cried a lot everyday... he (the patient) never brinks his eyes... severity pondered... could not describe...depressed...more strain, more stress."

2) Exhaustion: Exhaustion would happen to the family caregivers who had to care for the unable patients with no holiday or vacation and substitute from other relatives. Lack of support from health personnel as these nurses had to devote more time to assist and care for several critical patients and/or patients who had no family caregivers may also occur. Close relationships forged after being in the ward for a long time may have made the nurses unintentionally abandon these caregivers. Nevertheless, most family caregivers did not ask for any assistance. Some family caregivers narrated that:

> "...Sometimes...wanted to call a nurse...like when doing bed bath. During bathing...he had spasm... It is very tiring to complete bed bath."

> "Tired...because we didn't see any improvement from the patient. We had to care for him alone everyday. The patient could no longer perform self care."

3) Discouragement: In some cases, the family caregivers had to provide care to the patients alone without any support or aid from their family members. They had to face the stress and exhaustion from caring for the patients. Consequently, they felt that their family deserted them, pushed the burden on them, and did not pay any attention. They wanted their relatives to know what they felt and substitut care periodically to spare them ample time to tend to private business. One family caregiver felt discouraged as forced to accept caring responsibility by circumstances to care for her nephew. This caregiver told the nurse about her problem that.

> "his parents were not concerned about the problems. I stay put alone. I wish day and night… that he (patient)… could be out of the hospital soon.

4) Hope and despair: With prolonged caregiving, the patients' conditions were uncertain, either improved, deteriorated or stabilized. Thus, three family caregivers had experienced the swinging of hope and despair. During post operation, the family caregivers of a male patient with severe brain injury saw that the patient developed the complications of pneumonia and pressure sore and had been moved to intensive care unit for respiratory management for 22 days. After being discharged from the ICU, this patient had a high fever and later hydrocephalus that required cooperative care from the nurses and the family caregivers. After the operation for revised shunt due to infection, the patient gain consciousness, with no complications. Seeing that his response had increased the physician set a discharge plan. However, due to delay diagnosis, the patient had to receive the operation for Harrington Rod Instrumentation before discharge.

Such episode went on in the other cases. This happened because of the "had no idea" and "did not understand" of the information. It resulted from the fact that some family caregivers could not ask about questionable things, did not want to disturb the physicians and nurses who had overload of care for several patients, and could not find the suitable time to ask. In addition, there were many physicians and nurses working on the different shifts, so there was a chance to give contradictory/confusing information to the family caregivers. Consequently, family caregivers would be confused, misunderstand and not know what to believe, as a son of one patient said that:

> "Sometimes I did not understand... in the morning, nurses said one thing... and the doctor who rounded the ward would said another thing... the information was not the same... the doctor said that (the patient) should lie in the supine position, not get up. The nurses said that the head of the patient should be up."

Using medical terms which family caregivers did not understand was another cause of confusion:

> "...didn't get it...fear...did not dare to ask...what the doctor had said...would embarrass the doctor. As a result, I was anxious to care for the patient."

Promotion of family caregiver's participation in care

The promotion of family caregiver's participation in care in this period concerned the self-care ability development of the patients and maintenance of caring ability of the family caregivers. These included:

1. The patient's self-care ability development. The brain injury alters the atient's level of consciousness and cognitive impairment. Consequently, patients lose the basic attribution to ponder and decision making ability to do deliberate actions to meet the self-care demand. They also have memory defect and physical impairment such as weak extremities, unability to move by themselves, and have to stay in the bed which is complication-prone and undermines the recovery of patients. The appropriate recovery program would accelerate and enhance the recovery and self-care ability for patients. In this study, the rehabilitation of brain-injured patients focused on cognitive retraction by the cooperation of nurses, physicians and family caregivers appeared in the manual booklet for the rehabilitation of the brain-injured patients.

The rehabilitating procedures would start when the patients' conditions were stable according to the level of patients' cognitive functions which had been classified into eight levels including 1) no response, 2) generalized response, 3) localized response, 4) confused agitation, 5) confused inappropriateness, and 8) purposeful appropriateness.

The six patients categorized in the second and third level received the sensation stimulation including visual, auditory, olfactory, gustatory, coetaneous and kinesthetic to increase adequate stimulation to the patients' sensations. The personal favorite properties of the patient were used to stimulate the patients' memory. Moreover, precautionary measures would be imposed to prevent complications such as pressure sore, pneumonia, urinary tract infection, and contracture.

Moreover, there were nine patients who were in the forth to sixth behavioral levels. To this group, the managerial goals were to control the restless states and to provide an environment to decrease the sensation stimulation followed by the debriefing. To build a stimulating environment, the familiar remembrances such as people, times, and places were to be introduced. The daily living activities, exercises and range of motions were scheduled for the patients, accordingly. Lastly, daily living skill of five patients, classified in the seventh and eighth level, would also be promoted by allowing the patient to practice step-by-step until they could rely on themselves.

2. Continued knowledge and information provision. While in the hospital, the information related to patient's conditions, treatment, nursing care plan, and the prognosis were continuously and regularly provided by physicians and nurses to the family caregivers. This information would be the baseline data that shaped the family caregivers to manage their care performance. Sometimes, the information would be new and unfamiliar to the family caregivers to bridge the gap of the information they had, resolve the misunderstanding, etc. Interactive communication allowed the family caregivers and the health care team to maximize their mutual understanding.

3. Providing psychoemotional support. The family caregivers health status was found to be an effecting factor to caring ability. The findings revealed that the collaborative care produced great effect on stress, tiresome, discouragement, hope and despair among the family caregivers. Therefore, the psychoemotional conditions should be taken into consideration in this situation. It was found that nurse's concerns, attention, assistance, and provision of time also helped decrease the emotional depression of the caregivers. Acknowledgement of the family caregivers' devotions could encourage and empower the family caregivers' will and confidence to overcome the obstacles, and the loneliness could be eradicated.

4. Teaching and training. Nurses should enthusiastically and intentionally teach and train skills continuously. Expressing their concerns to problems of family caregivers establishes and maintains the good rapport with the caregivers and makes them feel free to ask questions. Nurses' assurance enhance the family caregivers' confidence, esteem and empower them to participate in caring for brain injured patients.

5. **Encouragment** It was found that providing information, allowing the family caregivers to participate in the decision making and caring activities, support, advise, exchange opinions and collaborative pandering and planning care encouraged the family caregivers to care for the patients. Evaluation of the practices increased the caring abilities and helped identify the affecting factors. For example, the mother of a severe brain-injured patient was not satisfied with the passive exercise and range of motions given. She noticed that the patient would be spasm during the exercise. Performing collaborative evaluation with the parent to prevent likely complications gave the mother a chance to learn and see the benefits of such exercise. "After we had not done (extremity exercise and range of motions) for 3-4 days.... The extremities seemed stiff and not easily moved," said the mother.

6. **Collaborative evaluation**: Providing opportunity to family caregivers to evaluate the patients' health status and their caring capability is necessary. These activities could increase the caregivers' in-patient care knowledge.

7. **Seeking for the support resources**: The origin of support resources for family caregivers would stem from their relatives. It was observed that some family caregivers informally aggregated during the break to discuss about the problem of patients and realties and to exchange opinion concerning the caring method. Sometimes they asked the family caregivers of the nearby patients to help substitute them for sometimes to do personal business. Moreover, during the follow-

up at neurosurgical clinic, the family caregivers would still share information with other caregivers. Therefore, the volunteer support group was set up to extend this resource. In addition, the in-charge nurses would act as key informants to give advice and suggestion in the meeting session: The exchange of attitudes, experiences and opinions were effective measures to improve the participating care. The understanding and knowledge gained in the meeting also helped decrease the problems and conflicts during hospitalization.

8. Reflection. This is a continuous strategy to empower the family caregiver to think, consider and decide freely. Nurses should actively propose problems, analyze the causes and consequences of the problems to find an appropriate solutions and strategies as well as perform the serial evaluation of the situation.

Factors influencing the family caregivers' abilities

1) Family support. The findings revealed that some family caregivers lived in the extended family with many children in the productive age to provide substitute care that eased the caregivers' stresses and anxieties. These supporters encouraged the patients to develop their self-care potentials. Having assistance in the caring and providing the food, running some errands and regularly visiting the patients encourage both the patient and the family caregivers, physically and emotionally, during hospitalization.

2) Hope. Participation in care sometime causes trouble some situation to the family caregivers because of the changing lifestyles. However, the data revealed that most of them accepted that these were for best to relieve their beloved from the suffering and illness. This hope encouraged and sustained the caregivers' will to care for the patients.

3) The support group. In this study, four family caregivers received encouragement from their support group. A family caregiver of a severe brain injured patient said that

> ".... Encouragement... from other relatives... It improved.. How long it will last... "
>
> "Encouragement from friend, a nurse, she had been through this suffering...more than...two years... recovering is time consuming..."

4) Reflection. This is a continuous strategy to empower the family caregiver to think, consider and decide freely.

The outcomes of the third phase

The evaluation of the results in the third phase demonstrated that patients had improved their conditions without complications in so far as their family caregivers could develop the patients' ability and provide continuous care to the patients.

1. The patients had a better recovery without complication. It was found that the mild brain injured patients regained their consciousness and were able to perceive the time, place, person and followed the command. There was only one patient who retained little confusion. All patients were able to perform daily living self-care activities, such as bathing, clothing, eating, eliminating, with minimal assistance from their caregivers.

In addition, it was found that all moderate brain injured patients had increased perception of time, place and person and partially understood their self-care in daily live activities. This group of patient required assistance from their caregivers as in the case of one patient who had early pneumonia and had been referred from a private hospital whose conditions improved after nursing staff, the multidisciplinary team and her family caregiver provided collaborated care and rehabilitation.

In severe brain injured patients, it was found that four patients increased their perception of time, place and person but they were still confused. They hardly understood how to perform self-care, therefore, assistance from the family caregivers was necessary. In this group, it was found that one patient had early pneumonia and improved after receiving the treatment and one patient had some prior complications such as pneumonia and urinary tract infection. Unfortunately, this patient had right arm contracture during the 20-week therapy; therefore, after terminating the caring in the third stage, pneumonia and urinary tract infection improved but his right arm was still contracted and required rehabilitation.

2. **Maintaining the family caregiver's ability to care for the patients.** It was found in the evaluation that the family caregivers could provide the caring quality to the patients without complications. The patients increased their interaction with environment, knowledge and understanding in daily living self-care activities. Additionally, report of the symptoms to the physician or nurses helped decrease the patients' abnormality/handicap. Although some patients had experienced complications, which delayed their recovery, the family caregivers were still able to handle the collaborative care for the patients. Reflection at the end of the process in

this stage revealed that the self-efficacy of the family caregivers was enhanced and the patients' health status was improved, as a family caregiver said:

> "...Felt that since we came to look after him (a patient), he had gradually improved day by day. Caring....then...helped him.. He improved"

The findings also indicated three different phases of care, since family caregivers started the caregiving until the termination of the third phase, depending upon the health status of the patients. The caring period for the mild brain injured patient was about 1 to 2 weeks, whereas that of the moderate brain injured patients ranged from 1 to 5 weeks. Moreover, the duration of severe brain injured patients ranged from 2 to 20 weeks.

Phase 4: Establishing self-efficacy before going home

After spending a certain amount of time in the hospital, the family caregivers were more familiar with the caring process. Patients gradually recovered and were ready to go home. Some family caregivers were confident and ready to take the patient back because they saw recovery and readiness in the patient. Examples of their sentiments are:

> "I'm so glad that the patient will get to go home. I am more relieved. The doctor wanted to discharge today, but I requested that it be tomorrow. We will be ready then."

> "The patient can eat, drink milk and he wants to go home. The doctor said if he could eat well, the IV would be removed. So, he requested that the doctor discharge him right away"

Some family caregivers believed that taking the patients back home was conducive for the recovery. Returning to the accustomed environment and familiar people would speed up the patient's recovery. One family caregiver mentioned:

> "I suppose going back home is good. The patient gets to meet other relatives. He will recognize things better. Here, he cannot really remember things. At first, he refused to speak. But on the day his sister came with her children, he started speaking. His sister said he could speak and started speaking since then."

Although happy, some family caregivers had some concern over the discharge of the patient, believing that taking the patients back home without full recovery created some difficulties to families. The patients may survive but there were no well-equipped life-support systems at home in case of emergency. Many were reluctant due to the fact that they would be on their own without hospital assistance. Some were scared of the waiting hardships. Many believed that hospitals were always a better choice as there were always health teams to offer assistance when needed. Other family caregivers were apprehensive that they would not be able to deal with serious situations that might occur to the patients. Such finding is understandable as most of the family caregivers in this study were from low income and low education groups. Their lack of financial support and knowledge seemed to aggravate this reluctance. More information and skill practice should be emphasized in order to lessen any complications that might occur. The following statements reflected their feelings:

> "I want some more advice on what to do when we go back home. I am concerned if the head will be affected."
>
> "I need a phone number to call when my brother has problems or the nurse may call one week before to remind of an appointment or call us every month."

> "I am very glad to see the changes in the patient's condition. I am glad that we can go back home but I still have some concerns on how to raise the hands and legs or check for phlegm."

The fact still remains that patients had differences in their backgrounds, symptoms, caring deficit and severity. Correct and thorough information should be given on each and every specific case. Each physically/psychologically disabled patient require different care strategies; therefore, each family caregiver need to have specific guidance to perform duties. Social supports somehow alleviate albeit not eradicate the insecurity.

In sum, three major strategies were identified in this phase. They are: 1) problem solving strategies to deal with the crisis at home, 2) where and how to locate support resources such as occupational training center, rehabilitation center, funding, counseling and guidance resources for emergency management, and 3) the caring skills improving strategies for the family caregivers and family members.

Promotion of the family caregiver's participation in care

The preparation of the patients and the family caregivers to gain self-efficacy that enables them to manage the problems are differently tackled as follows:

1. **Providing additional instructions and training on the skills that seem to be problems.** Readiness and confidence in the patient and their family caregivers can be achieved by providing additional instructions and knowledge, practice of skills through teaching, demonstration, consultation, suggestions on problems, review on the practice or review on the knowledge that can cause problems for the families. Nurses should give patients and their family caregivers an opportunity to ask the questions of their concerns. Coordinating with nutritionists,

psychiatrists or physical therapists to provide instructions or practice in specific complicated skills could increase higher confidence among the family caregivers.

Although evaluation of the opinions on caring and caring plans after discharge indicates that the family caregivers have understood the illness, treatment and instructions on caring for the patient, nurses still have to determine whether some additional instruction might be needed. Recording of the patient health profile and detailed symptoms and conditions would be helpful for the follow-up, either by phone or at appointment in the hospital. Information should include discharge date, name of patients, diagnosis, Glasgo Coma Scale, illness condition the day prior to discharge, problems that need a follow-up, instructions prior to discharge, name of family caregiver and his/her phone number and contact address and name of nurses.

2. **Primary problem-solving guidelines**. Instruction leaflets on the observation techniques for abnormality of nervous system and complications would be given when patients are discharged. The phone numbers of the Neurosurgical Ward and the nurse who is in charge of follow-up visits and telephone consultations are also included. Understanding of the guidelines provided in the manuals must be maximized to ensure the ability of the family caregiver to perform the care. It should be emphasized that if the abnormalities or uncertainties are observed, the family caregiver must bring the patients to the hospital immediately. The family caregivers should be informed that they can contact or consult the nurse any time if needed.

Nurses would also provide warnings about the complications or caring for problems that might occur at home to create better awareness in the family caregivers, which will lead to better prevention and management if such situations occur. Nurses and family caregivers mutually select appropriate practices and seek appropriate resources when problems arise.

3. **Facilitation of referral.** It was found that 12 patients lived upcountry, some as far as 780 kilometers from Bangkok that prevented the patients from keeping appointments or requesting assistance. In such cases, nurses needed to plan for the patients and their family caregivers so that they would have continual care and assistance. This was done by coordinating with physicians to prepare the historical record of the patient, which included name, age, sex, injury history, diagnoses, symptoms, treatment, operations, illness condition, current treatment and existing problems that required follow-up. This record would help the family caregivers to seek referral follow-up from other hospitals.

Factors influencing the family caregivers' abilities

It was found from reflecting on this phase that the caring experience in hospital and the level of patient's recovery affected the family caregivers' confidence.

1) **Caregiving experience in hospital.** It was found that readiness preparation for the family caregivers created confidence in the family caregivers. The training gave the family caregivers on-hand caring experience, which affected the self-efficacy to perform the care at home. They also got experience while in the hospital as they had a chance to learn, observe, ask questions, try and practice their skills with nursing personnel.

2) **Patient's recovery.** This factor also had great impact on the self-efficacy of the family caregivers to provide home care. It was found that family

caregivers whose patients were in a good recovery condition had more confidence in providing care for patients because the care provided was simple and required no complicated skills or knowledge, and easy for the family members to provide rotation care. Family members could go back to their daily responsibilities. Patients with abnormal behavior or those who required complicated and long-term care worried their families more.

Outcomes of the fourth phase

It was found that the majority of family caregivers were ready and confident in taking the patient back home. They often immediately accepted the discharge decision on the first day although some had asked to have the patients discharged the next day because they needed time to prepare the home environment. Some family caregivers took 2 to 5 more days to practice preparing liquid food, exercising for weak arms and legs, moving patients, and sitting down, standing up and walking the patient. There was only one case that took 11 days to practice the liquid food preparation, preparing the home environment and claiming for medical expenses.

Phase 5. Self-support

This ability was expressed in every family participating in this study. "I am ready to take the patient home," said one family member. This same expression was also readily given by family caregivers at follow-up sessions, which confirmed the self-support ability the family caregiver had gained. However, the study also revealed that the duration family caregivers took in gaining this ability varied according to the levels and types of disability each patient sustained. If the patient had a good recovery before returning home, the family caregivers would generally be ready to have the patient back. On the contrary, if the patient was still in a severe condition with technological dependence, the family caregiver needed more time to gain this self-support ability before they could take the patient back.

Families' self-support that was found in this study could be described in four criteria. The family caregivers should be able to: give verbal instructions; seek appropriate resources such as information, financial assistance, etc. when needed; find someone to turn to when they need help; and build up their own competency to the point where the patient can feel confident of proper care.

Promotion of family caregivers participation in care

1. The telephone contact. Nurses should perform follow-ups to assess problems and obstacles in providing care for the patients or the patients' ability as well as to evaluate the performance, distinguish the problems and consult or advise the family caregivers. These can be done by phone. If the telephone follow-up is not possible, then, a follow-up should be done when the patient comes back to the neurosergery clinic for the appointment 2 weeks after discharge.

In this study, it was found that some family caregivers sought advice over the telephone, while some came in person. Information usually reported was the abnormalities obviously observed in the patient. They asked for suggestions, solutions and alternatives to solve the problems. Some family caregivers also reported the patients' progress. All of this information was noted in the record of the patient.

2. Home visit. A patient visit was done on one case in this study in order to observe the environment and living pattern of the patient and the family caregiver that affected the observation of the treatment plan. The assessment was carried together with the family caregiver to determine if the suggestions from the nurse and the planned treatment could be applied at home. Then, adjustment was implemented to best suit the changes in the living and injury condition of the patient.

Outcomes of the fifth phase

It was found that every family caregiver was able to achieve self-support. Some patients were able to recover and take care of themselves within 2 weeks. One patient had a bed-wetting problem prior to discharge due to his cognitive impairment. He was not able to clearly communicate when he needed to urinate. Nurses and his family caregiver were involved in finding solutions to the problem. The patient's father finally decided to leave a chamber pot in the bedroom and tried to observe the patient's behavior to find the urination indicator of the patient. Frequent askance also help. Five days after discharged, the father reported, "He wet the bed only once. After that, he was able to tell us and we helped him to the toilet." When the patient came back for the appointment two weeks afterwards, it was found that he was able to walk without assistance and take good care of himself. In addition, some other family caregivers still had to provide care and try to build up the patients' ability to self-care. Towards the end of the study, it was concluded that family caregivers were able to provide continual care for the patients. They were able to solve the problems and seek assistance when needed. Patients' need for care was responded to and this led to better recovery. One patient, who gained very slight consciousness, and who was tube feed and had contracture in the right arm, needed his mother and brother to provide daily activities. They assisted him to clean, prepare food, tube feed, and exercise his arm and leg muscles. Some were also able to continue their own daily work selling food in their shop and carry on other social interactions. As for the deficiency corrections and physical rehabilitation, the family sought consultation and assistance from the Medical Rehabilitation Clinic. Data from the follow-up indicated that the patient was able to utter sounds and learn to stand and walk.

In conclusion, the process of family participation in caring for the patients with brain injury reflected the effort and time the family caregiver needed to cope with their own stress as well as to learn and develop their caregiving abilities. In these processes, the patient moved from the first phase of more dependence on nurse and other health care team to the last phase of more independence.

The patient's lifestyle after hospital discharge

The follow-up data on the progress and lifestyle of the patients revealed that although many had recovered, some could not gain self-efficacy. They still needed assistance from the family caregivers and the family members. Some could return to normal life. One teenage patient had to drive the motorcycle to the school, as the transport system was difficult. An interview with this patient revealed that this patient still did not wear a safety helmet, as he did not like it. He, then drives with better precaution. Driving speed was also reduced and observed. Another patient still had weak limbs and tried to learn how to drive a bicycle. His mother narrated that his left hand could not function properly and he had difficulty controlling the driving and sometime he fell.

3. Impact of the model on participants' perception and satisfaction

1. Nursing staff's perception and satisfaction

After the nursing staff had developed a care model and changed their nursing behavior according to the model for family caregivers' participation in caring for traumatic brain injured patients, the nursing staff gained perception and satisfaction towards their observation of nursing patterns listed below:

1.1 Perception and satisfaction of benefit received

a. Promote efficiency in the nursing service. Regulating nursing service systems that involve cooperation with other health care providers and encourage family caregiver to care for the brain injured patients to give the first priority to the patient and family seems to create better relationships between nurses and family caregivers. Family caregivers increase the trust for the nurses. With this friendly relationship, the family caregivers are more likely to discuss, share their opinions and request things they need. In this study, this kind of atmosphere led to a better cooperative environment conducive to caring for patients. Nurses were also able to meet the patient's and the family caregiver's needs. This promised better results of the patient's health. Some nurses mentioned:

> "This gives the family a chance to speak with us and express their opinions. We are able to offer better nursing care that meet the patient's and the family's needs. This is an advancement in nursing."
>
> "They (family) get to know what the patient has done. It is also an opportunity to check with the nurse as the family will ask for reasons why something must be done. They can also inform nurses of problems because they get to see patients everyday."

> "I think the family is a great help to provide care for the patients. They are very satisfied seeing that the patients are getting better."

Since most patients are in a critical condition which require complicated care and since it is apparent that the need for care and the allotted time of the nursing team is not always sufficient, the involvement of the family caregiver in doing simple and less complicated tasks is of great value. The family caregiver could assist the patients to perform their daily activities, observe any abnormality, or even perform some complicated tasks after being trained to do so. This cooperation between the personnel in health care team and the family caregiver could prevent accidents and other complications. As such, in this study, the time spent for hospitalization was also shortened and the nursing expense decreased. Some nurses mentioned:

> "It is good that the family can help look after the patient. Sometimes, we cannot offer very thorough care. For example, they can help wash the patient with towels. We show them how and they can do it. They learn the techniques in giving proper care. Sometimes they inform us when the respirator get disconnected and the patients get a shock."

> "I think it is a great idea that the family gets involved. We don't have enough staff. Some wards are careless in their practice, which leads to accidents. It depends on how the nurses get the family involved. This is not wiping away the burden of nursing. The nurses instruct and suggest on the care."

> "They (family) can help, particularly with a chronic patient with suction or tube feeding."

> "The patient could recover faster when their family get involved in the nursing care. They have the will to live, their family want to see them recover, the

> hospitalization time is shortened, the expenses decrease and the family can go back to work sooner."

b. Self-development. In this study, the nurses found that having the family caregiver involved in caring created a realization in one is own development. They had to seek for more knowledge in order to offer consultations and suggestions so that the family caregiver would have a better understanding of caring, as one nurse mentioned:

> "I must advise the family on how to take care of the patients. In some aspects, I simply don't know and must find answers in textbooks or ask experts so I can explain to the patient's family. I myself also learn new things."

Throughout the research process, the personnel in the health care team regarding suggestions and practice of patient care always asked the investigator for consultations, suggestions, help or solutions to problems. Furthermore, it was found that nurses often asked physicians and shared their opinion and information on problems in performance reflection meetings.

Role models from colleagues and performance reflection meetings leads nurses to realize that they should always attempt to continue to learn and perform self development in order to enhance quality of care. Consequently, the families will accept nurses. This can be done in the form of nursing service development or significance given to the protection of rights of patients and their families. Some nurses said:

> "I am impressed seeing other nurses talking and explaining matters to the patient's family. So, I try to improve myself because I want the patients and their families to be impressed with me."

> "I had never spoken to the unconscious patients because I thought they would never hear me but then, I saw 'Ang' (a nurse's name) always talk to the unconscious patients. The patients' families were there. They saw this. They were all impressed. So, I started doing the same. Now, I am speaking to all patients, conscious or unconscious. The families might be impressed by the way I talk."

c. **Enhance family caregiver's abilities.** Nurses agreed that involving the family caregiver in caring for patients enable the family to gain more experience that helped them develop their potential to provide continual and proper home. Some nurses mentioned:

> "They (family caregivers) learned and experienced new things in caring for the patient. They met families of other patients and shared ideas."
>
> "When the families came, we had a chance to mutually plan for the discharge so that they knew what to do when the patients left for home. We showed them. They tried simple tasks and worked their way on more complicated tasks. If we drew the plan before the discharge, the families might not be able to learn all."
>
> "This is good for the recuperation of the patient. When the patients go back home, their families play an important role in their care. We can teach families on the physical care and exercise for the patients. The families will be able to do this as they are familiar with it after training."

d. **Being proud of themselves and profession.** As a result from fully performing their nursing practice, sharing ideas, changing to more constructive nursing methods and realizing the positive result of their practice, nurses were proud of themselves and their profession. They were happier with their work. Some nurses explained:

> "Before discharging, I taught the family to take the patient's temperature according to the instructions (given to the family on how to observe abnormalities of nervous system) so that they will be able to do it at home. You know what? The family was so pleased as no one has ever bothered teaching them. I think it is something that they would be very proud of. We taught them to take care of the patients rather than waiting for help from the hospital. It is a change in their attitude. They learned to care for the patients at home."
>
> "When the patients came to see me, I am very proud of myself that I have helped them. I value my profession more."

1.2 Perceived difficulties

In developing a care model for family caregivers' participation in caring for traumatic brain injured patients, nurses encountered the following problems in their nursing patterns:

a. Lack of confidence in the knowledge and skills in caring for the brain injured patients. A major perceived berrier for nurses at the beginning of observing nursing patterns was the lack of knowledge. This became a problem when consulting with the patients' families. Most of the nurse practitioners had less work experience. Some had just graduated; others had just been rotated from other departments. But caring for patients with brain injuries was a very complicated task, which required special knowledge, skills and experience to make decisions in solving problems and planning care. When nurses lack knowledge and skills, they were not confident in their work. They encountered difficulties giving consultations. Some nurses explained:

> "The problem is from me. I don't know what happened to the patients. I don't have much knowledge

> in this field. I must consult with the doctor most of the time."
>
> "When the patients' families ask questions, I am not very confident in answering them. I am not sure I have a good understanding of the situation."

c. Heavy workload. In some situations, there were too many critical patients that required urgent nursing care. Nurses could not fully perform their work, which led to inefficient care. This led to the insufficient time given to patients and their families. One nurse explained,

> "Sometimes, there were 10 patients on respirators. It was very busy and we simply didn't have time to communicate with patients and their families."

Moreover, there were still many other responsibilities from the Nursing Service Department that required the nurses' share. These shared responsibilities are meetings with other agencies, tasks not related to nursing such as statistical collection, instrument inventory, and requests for medicine and medical supplies as there were no clerks responsible for these jobs. Thus, all tasks were considered nurses' and they must schedule them into their work shift. Most of the nurses' time had to be allocated for other works. "The problem is the nurses' heavy workload. The task in approaching patients' families and teaching them seems to have low priority," one said.

2. Family caregivers' perception and satisfaction

Data from the interview with the family caregivers revealed that they were satisfied with nurses' caring behavior, involvement of the family caregivers and the result on the patients' health.

a. **Satisfaction toward nurses' caring behavior.** Family caregivers agreed that most nurses had good manner toward patients and their families. They used polite words, had good human relations, cared, paid attention, encouraged, assisted and facilitated the family caregivers. Family caregivers had their voices recognized in the caring of the patients. Family caregivers felt more relaxed and satisfied with the service. Some family caregivers expressed:

> "The doctors (physicians and nurses) in this building are very good. They speak politely, care for patients, explain things well and offer suggestions."
>
> "I don't feel stress, but at ease. When I ask them to take a look at my wife, they always come as requested. They helped make the bed. I think this situation is greatly beneficial to the families."
>
> "Everyone (nursing personnel) here are very responsible and friendly. When you request for help, they are right there. Both female and male nurses are very impressive. They are diligent and active. The nurse's assistant (nurse aids) help with cleaning the patient. They are very nice."
>
> "At first, I thought the nurses would not give too much care. But once I was involved with them (nursing personnel), they really gave good care even though they are government hospitals. The nurses and assistant nurses offered suggestions. I didn't know how to change the patient's clothes or bed sheet. I was very worried then. But now I am more confident."

Some family caregivers indicated that they were not impressed with some nurses' behaviors as they were not very attentive. One family caregiver indicated:

> "Some were very good. Some weren't. Some you didn't have to wait for at all. Some just took their time."

b. Satisfaction with the involvement in in-patient care. The family caregivers found that they were empowered and given a chance to participate in decision making on the treatment, negotiation and performing patient care. The family caregivers realized the benefits, were more cooperative, and felt more satisfied with the involvement:

> "It is good and beneficial. I get to offer care. I get to know the patient's symptoms. At first, I didn't recognize any symptoms. But later, I see the symptoms in the patient."
>
> "At first, the nurses instructed and suggested. They did most of the work such as changing clothes and bed sheets. Now, I can do it. I am satisfied with this."
>
> "The doctor prescribed physical therapy. I got to perform it along with the doctor. … I am very satisfied. He (physician) asked before he ordered to have anything done such as x-rays. I am very satisfied."

c. Satisfaction with patient's outcome. With the family's involvement in patient care, the patient's recovery was better. This was due to the cooperation of the family caregivers, nurses, physicians and other care providers. The family caregivers had a better impression of the treatment and were more satisfied. Some family caregivers said:

> "From the first time I saw the patient, the condition has improved. Right now it is good. I am very glad."
>
> "I am very happy to see that he has gotten better. I think having the family offering care is really great. I am very pleased."
>
> "I feel that after I am here to take care of him (the patient), he is gradually getting better. Caring for him makes him get better."

> "I am so pleased. This is great. The patient is getting better. It is worth the caring and the time away from work."

d. A comparison of the family caregivers' preference, actual participation, and satisfaction with participation in patient care.

Testing of the statistical difference revealed that the mean scores of family caregivers' preference at the date of hospital discharge was significantly higher than the date of admission mean scores at the level of 0.05. The mean scores on actual participation of the family caregiver at the date of hospital discharge was significantly higher than the date of admission mean scores (t = -6.037, p < 0.001). Similarly, the mean scores of family caregivers' satisfaction with participation significantly increased at the date of hospital discharge (t = –6.133, p < 0.001). Details are in Table 5.

Table 5 Comparison of mean distribution of the family caregivers' preference, actual participation, and satisfaction with participation in care between date of admission and hospital discharge (n = 22)

Variables	X	SD	t-value	df	p-value
Caregivers' preference					
Admission	96.77	9.29	-2.376	21	0.027
Discharge	100.05	10.52			
Actual participation					
Admission	75.59	12.82	-6.037	21	0.000
Discharge	85.59	12.65			
Satisfaction					
Admission	89.18	11.93	-6.133	21	0.000
Discharge	100.09	10.94			

3. Impacts of the model on recovery levels of traumatic brain injured patients

3.1 A comparison of mean distribution of Modified Disability Rating Scale between date of admission and hospital discharge

The finding revealed that the mean scores of Modified Disability Rating Scale was 17.95 (SD = 7.03) at the date of admission, and this significantly increased to 28.90 (SD = 4.44) at the date of hospital discharge (t-value = 9.144, df = 19, p-value = 0.000). Details are in Table 6.

Table 6 A comparison of mean distribution of Modified Disability Rating Scale between date of admission and discharge

Variable	X	SD	t-value	df	p-value
Admission	17.95	7.03	9.144	19	0.000
Discharge	28.90	4.44			

3.2 Length of hospital stay

Length of hospital stay was presented in Table 7. It was classified according to severity of brain injury. The patients sustaining mild brain injury stayed in the hospital ranging from 8 to 14 days with a mean of 10.86 days (SD = 2.48). The patients with moderate brain injury stayed in the hospital ranging from 9 to 36 days with a mean of 16.00 days (SD = 9.59). The average number of hospital days in the patients sustaining severe brain injury was 48.33 (SD = 52.07) with a range of 14 to 148 days.

Table 7 Length of hospital stay

Severity of brain injury	LOS (days)	X	SD
Mild brain injury (GCS 13-15 score)	8 - 14	10.86	2.48
Moderate brain injury (GCS 9-12 score)	9 - 36	16.00	9.59
Severe brain injury (GCS 3-8 score)	14 - 148	48.33	52.07

3.3 Complication of the traumatic brain injured patients

Before the present admission, two patients had developed complications from transfer from a private hospital—one patient had developed pneumonia, and another one had developed pneumonia, urinary tract infection, and infected surgical wound. After receiving treatment, the patient with pneumonia had improved, but the other one developed contracture of the right hand, elbow, and shoulder joint during hospitalization. Furthermore, it was found that two patients developed complication during hospitalization—one patient had pneumonia, and another one had pneumonia, urinary tract infection and pressure sore. The details are shown in Table 8.

Table 8 Complication of the patients who obtained the participated caring model

Severity of injury	Respiratory infection no (case)	Urinary infection no (case)	Pressure sore no (case)	Contracture no (case)
Mild brain injry	-	-	-	-
Moderate brain injury	-	-	-	-
Severe brain injury	2	1	1	1

3.4 The total expenses for hospitalized health services

The finding from the study revealed that the total expenses for hospitalized health services of patients with traumatic brain injury were high. The total expenses for hospitalized health services of patients sustaining mild brain injury were ranging from 6,865.00 – 35,518.00 baht with a mean of 19,449.43 baht (SD = 9,971.29). The total expenses of patients with moderate brain injury were ranging from 13,748.00 – 31,675.00 baht with a mean of 19,467.43 baht (SD = 5,690.16). The total expenses of patients with severe brain injury were ranging from 15,450.00 – 242,536.00 baht with a mean of 68,999.17 baht (SD =89,419.15).

Table 9 The expenses for hospitalized health services

Severity of brain injury	Expenses for hospitalized health services (Thai baht) Minimum-Maximum	X	SD
Mild brain injury	6,865.00 – 35,518.00	19,449.43	9,971.29
Moderate brain injury	13,748.00 – 31,675.00	19,467.43	5,690.16
Severe brain injury	15,450.00 – 242,536.00	68,999.17	89,419.15

4. Impacts of the model on other care providers

The model for family caregivers' participation in caring for traumatic brain injured patients is an attempt to revamp the nursing service system. It encourages family caregiver's involvement in caring for patients in every step of caring process while staying at the hospital until the patient returns home. It involves teamwork from the multidisciplinary team. This model has an impact on personnel of the multidisciplinary team: neurosurgeon, psychiatrist, physical therapist, nutritionist and social worker.

4.1 Neurosurgeon

Data obtained from the observation and the interviews of three neurosurgeons and four residents in neuro-surgery revealed that there were two areas that impacted the physician team: treatment service and teaching system.

1) Treatment service

a. Information and decision on treatment. All physicians agreed that family involvement offered better results on the instructions and decisions of the treatment. Physicians were able to offer information on the patients and learn about the family's decision. The family caregivers were also able to indicate their observation of the patients, ask questions and inform the physicians about their decisions. This kind of exchange of information facilitated the treatment. "Having the family around all the time offers a chance to get information from the family right away." The physicians agreed that offering information created better understanding of the treatment. It was the family's right to make the decision. Physicians must accept and respect the rights of the patients and their families. This reflected the change from the traditional medical model. A physician explained:

> "We should offer information that promises benefit and good results. We give information and the decision comes from the family. We should not force or dictate them. It is their (patients' and families') lives. We only suggest and are ready to help."

It was also found that the exchange of the information between the physicians and the family caregivers took a considerable amount of time, which directly affected the physician's schedule. Physician's schedules were filled with urgent cases, patient visits, clinical works and operations. A physician mentioned,

> "We are willing and would like to discuss treatment with them. But some families seemed to talk too much. Question after question and they never seem to understand. This is beyond our scope because we won't be able to do other work."

However, this can be solved as many said "Nurses must help clarifying it with the families." Nurses allowed family caregivers a chance to talk and explain problems. They can help assess the perceptions and needs. Then, information could be given to best match the needs and offer the greatest benefit to the families.

b. Treatment. Most physicians found that family involvement was not a problem or obstacle to treatment. Some physicians did not like having family caregivers around the patients, especially when they had to perform some treatment while the patient was in the bed. They felt the place was too crowded, not conducive to their work and that it might accelerate the spread of germs. If physicians needed to perform in-bed treatment, family caregivers were asked to leave the room for a moment. The family caregivers were very cooperative on this part. A physician indicated, "It is not obstructive. No problem. If we need to do any procedure, we simply ask them (families) to wait outside." Another physician added, "I feel a little inconfident when the families are watching. When I need to perform invasive procedure, they will be asked to wait outside." Another added, "I am afraid that the family could spread germs."

2) Teaching system

As the Neurosurgical ward is a training place for residents in neurosurgery, this model has an effect on the training of the physicians, especially on grand rounds or patient visits by neurosurgeons and resident physicians every Tuesday around 8.00-10.00 a.m. During these visits, discussions are carried out on with the topic of symptoms, diagnoses, treatment plans and the results right at the patients' bed. These discussions and the medical terms used cause a lot of confusions for family caregivers that are not accustomed to it. From the observation in this study, several changes were made to facilitate best results. It was agreed that family caregivers would be absent during this periods whereas discussions that might have affected the patients would be done at the nurse station. "There is no problem. If we don't want to discuss treatment in front of the patients, we will do it at the nurse station or the film reading area." The results of these discussions would be given to the families afterwards.

Physicians generally viewed family involvement as a development in their potential to offer continous home care. This would promote better recovery, especially those that needed longer recovery periods in particular. It was an encouragement for patients as well. Some physicians mentioned, "Family involvement is good, especially in chronic cases. They get to monitor and learn to offer care for the patients," and, "Family is an encouragement for conscious patients."

4.2 Psychiatrist and physical therapist

Psychiatrists and physical therapists found that family involvement helped develop skills in family caregivers to provide continual care at home. This could affect the recovery of the patients. At the beginning of this research, the psychiatrist agreed and planned a therapeutic program that focused on recovering functions of the patients. The physical therapist gave physical rehabilitation to the patients and taught some skills to the family caregivers such as tapping the chest, moving the patients and exercising arm and leg muscles and joints. Due to the heavy workload at the Department of Medical Rehabilitation, the psychiatrists and the physical therapists could perform services only to those referred by neurosurgeons or nurses. The therapy was given in the ward for the critical cases and those who could not move. For those who could move around and/or whose therapy required special machines, they were sent to the Department of Medical Rehabilitation. The family caregivers got to consult and get suggestions from them. They were also trained on the rehabilitation process and physical therapy for the patient.

4.3 Nutritionist

Nutritionists managed the type, quantity, and nutritional value of food and energy required for patients with traumatic brain injuries to meet their needs while the patients were hospitalized. This also included consultations, suggestions and practice given to the family caregivers in prepare liquid food and tube feeding prior to discharge when referred by the nurses.

4.4 Social Worker

In this study, most patients with traumatic brain injuries came from middle to low income families. The high cost of treatment, medication, diagnosis and treatment, which involved high medical technology, was a problem for the families. Even though patients were given some compensation from insurance, it could not cover the total expense. Some families must pay for some of the expenses. They needed financial aids from other sources. It was found that 9 cases had to be referred to the social worker for consultations, suggestions and help facilitating support from the government. This also meant a follow up with the families that were seeking financial help. It was also found that self-support groups created some misunderstandings in exercising their rights to seek support from the hospital and/or government. This increased workload to the social workers.

In conclusion, a change in the model for family caregiver participation in caring had both positive and negative impacts on the multidisciplinary health care team. The neurosurgeons found that this involvement was beneficial in information provision, decisions on the treatment, and the development of the potential of families in caring for the patients. This promised a better result on the patients' health. But this model caused some changes in the service and teaching system. Psychiatrists and physical therapists had to give consultations and train the families to perform rehabilitation or physical therapy tasks. Social workers had to spend more time and energy to serve the needs of the families.

Sustainability of the Model

After implementing the collaborative care model for 2 years, the investigator was able to conclude that the model can be continuously implemented.

1. This collaborative care model was endorsed and incorporated in the upgrading of quality service of the Bhumibol Adulayadej Hospital. The Neurosurgical Ward responsible for implementing the model was proclaimed as the pilot ward in providing the family caregiver participation care to the patient.

2. The budget to produce the demonstration videotape to educate the family caregiver of caring procedures and to train them with the caring skills was required. This production was a coordinate project between the nurses of the Neurosurgical Ward and the physicians from the Department of Surgery.

3. The practice in this model was adapted in the other wards such as the Medicinal Ward in providing care to the elderly, the chronic illness, and the stroke patients. The telephone follow up was also adapted in some other wards.

4. The Orthopedic surgery and nurses proposed the Service Development Project based on the multidisciplinary care model similar to this research model to upgrade the nursing care to the spinal injury patient. The researcher was invited to participate in this project.

5. The demonstrator team recruited from the experienced family caregivers was set up to help train the other family caregivers. This group also conducted the discussion group to share their knowledge and experiences to the new caregivers.

6. The support group was formed to build a care network. They donated the unused devices such as axially crutch, walker, etc. that the patients did not need to the others who needed them.

CHATER V

DISCUSSION

This discussions of the research results are divided into seven parts: 1) characteristics of the participants; 2) The model for family caregivers' participation in caring for traumatic brain-injured patients; 3) the process of model development and influencing factors; 4) impacts of the model on participants' perception and satisfaction; 5) impacts of the model on patients' recovery; 6) contributions to knowledge development; and 7) lessons learned by the investigator.

Characteristics of the participants

The participants in this study comprised of 30 nursing staff and 22 family caregivers who rendered care to 20 traumatic brain-injured patients.

The nursing staff: Most of the nursing staff had the following profile: aged between 21-29 years; were registered nurses, technical nurses or nurse-aids; had between 1-26 years of experienced; had worked in the same department between 1-11 years, with 18 nurses stationing in one unit between 1-3 years due to the 1 to 2 year routine rotation policy. This rotation policy was meant to maximize the efficiency of the personnel according to one's expertise as well as to appropriately allocate senior nurses to maintain the equal distribution of the number of staff according to the work load in each unit. This staffing strategy was conducive to the annual promotion procedure and the study leave ration. However, this type of personnel management was contradicted to what Benner has suggested.

The results of a qualitative study on the nurse experience conducted by Benner (1984) revealed that appropriate service duration that allows the nurse to acquire knowledge, efficiency, skill and nursing practice experiences is as follows: the advanced beginner, who had between 1-2 years of experience, could provide satisfactorily nursing care, better cope with various crisis, could analyze elements of problem but still could not differentiate the level of severity of the problem and rather be the rule-oriented. The competent nurse was those who had been with one unit for 2-3 years, could be able to develop the effective nursing care plan and could set up the long-term objective for the plan. This group could produce critical thinking and making certain decision concerning nursing practice fairly well. However, this ability was sometime not enough to the level of holistic perspectives and they still could not prioritize the problems, which prevent them from engaging in the immediate decision making and problem solving.

Nevertheless, the collaborative care that propels nurses to closely work with the other care providers collaboratively or multidisciplinanly with the hand-in-hand assistant from the family caregivers allows the concerned parties to learn, develop, and exact each potential to the full. This type of collaboration has been proved to be one effective strategy. Use of the collaborative care model increases caring ability of the nurse and the family caregivers. In the present study, most of the participants were satisfied with the result of the nursing intervention provided.

The family caregivers: The 22 family caregivers were purposively selected according to the predetermined criteria. Sixteen were female and the rest, the other six, were male. They were aged between 40-53 years, and were the spouse or parent of the patient. Most of them came from the province and had a helping hand from other family members to alternatively provide care to the patients. This finding was similar to the findings of several studies (Acorn, 1993, 1995; Campbell, 1988; Grant & Bean, 1992; Intorn, 1996; Songwathana, et al, 2000). Data gained from these studies revealed that most of the family caregivers of the traumatic brain-injured patients were females, either mother or wife of the patients. Phuphaibul (1996) pointed out that this practice derived from social beliefs and cultural values that expect the female member in the family to care for the sick person especially for the young and the elderly.

The lifestyle and the type of works in particular affected the time allocation and the role taken by the family caregivers. It was found that most of the family caregivers were the vendor, employee and agriculturist. This finding was in congruence to the findings of Intorn (1996) and Shawong (1992) which also found that most of the family caregivers were employees and agriculturists and their occupations were flexible. They could easily refrain from or resume work at their owns command or could relinquish the work to someone else. Suwanno (1997) and Hirunchunha (1998) also found that most of the family caregivers of the stroke patients who received treatment either in the hospital or home care were agriculturists, employees, self employed and unemployed. These types of occupations are flexible and seasonal and can be replaced by someone else if necessary, thus it leaves them enough time to care for the patient, both in the hospital or at home.

In a big family with several members, those who are in good health would be expected to be the caregivers more than the others who are not as healthy, as caring for the patient requires strength and patience. Those who used to care for the patient are also expected to take the family caregiver role as it is believed that experienced caregivers could provide better care than the novice.

The traumatic brain injured Patients: Among the 20 traumatic brain-injured patients, there were 13 males and 7 females whose age ranged from 13–72 years. Fourteen of them were teenagers and young adults. They were employed and some were studying in school. Seventeen patients had been injured from car accidents especially from the motorcycle. These findings were congruent to the findings from various studies in the Thai context (Assawapat, 1996; Intorn, 1996; Kijmahatrakul, 1999; Promkuntong, 1997; Shawong, 1992; Tangchivittaya, 1999; Tepahudee & Pheuenpathorn, 1999) and in the foreign context (Acorn, 1993, 1995; Grant & Bean, 1992) in that most of the traumatic brain-injured patients were males in the early adolescence or early working group, and most brain injury suffered from motorcycle accidents. This is due to the fact that this group usually rides a motorcycle more than the others (Petcharoen, Wonggrasrithong & Udomchairat, 1998; Tanmukyakul, 1985). Being young, they usually take risk are careless and seldom have self-prevention. Some have less driving experience, like to speed, do not wear a safety helmet or wear it improperly (Petcharoen, Wonggrasrithong & Udomchairat, 1998). Drinking alcoholic beverage before or while driving is also a cause of accidents (Wirojanasangaroon, 1996) as alcohol in the blood cell reduces the maneuvering ability of the person and increase the person's proneness to accidents (cited in Punyahotra, Potipuntaracha, and Chareonroy, n.d.; Tanmukyakul, 1985).

Furthermore, it was discovered that most of the patients in this study had intracranial hemorrage which was congruent to the study of Tepahudee & Phuenpathom (1999) but was contradictory to the study of Kijmahatrakul (1999) who found that the pathology usually found among the brain-injured patients was cerebral contussion. There were 3 groups of patients in this study: 7 severe brain-injured patients; 7 moderate brain-injured patients; and 6 mild brain-injured patients. The different levels of injury cause different pathology corresponding to the level of severity and require different types of care. The findings of various previous studies (Jonnes, 1981; Kijmahatrakul, 1999; Tepahudee & Phuenpathom, 1999) have revealed that the traumatic brain injury causes various physical, cognitive, intellectual and behavioral limitation and deficit, thus it affects cares and duration of recovery. The concept of dependent care in Orem's General Nursing Theory (1995) has posted that the health-deviation self-care requisites arise from feeling of illness, a disease or injury, specific forms of pathology, and being under medical diagnosis and treatment. When the demand of action for self-care exceeds the patient's capacity to act, a self-care deficit exists. This situation could be temporal among the acute patients or could last longer or even become life-long among the chronic illness patients. Therefore, the patients inevitably need or have to rely on the dependent care agent, which is the family caregiver.

Model for family caregivers' participation in caring for traumatic brain injured patients

The major finding in this study is the model for family caregivers' participation in caring for traumatic brain-injured patients derived from undergoing the reflection process among the concerned parties. The nursing staff, other care providers, and the family caregivers joined in the processes of reviewing and analyzing the problems, selecting and adjusting the alternatives to correspond with the patient's needs and illness status in order to maximize the care outcomes. This collaboration model began in the Neurosurgical Ward through the discharge and continued through the following up period at home. This democratic care model which is different from the conventional care model emphasizes the empowering of each participant. Conventionally, the health problems, the care, and the outcomes are usually predetermined by the nurses. However, the new model reduces the dominant role of the nurse to become partner of the team and increases the role of the care-givers. The caregivers are expected to have more responsibility to care for them and help each other to effectively care for the family members. In addition, this collaborative care model reflectes the professional practices of the nurses. Nurses integrate nursing knowledge and related knowledge into their clinical practice and function in collegial relationships with physicians and other health professionals. They conduct comprehensive care, and demonstrate autonomy and accountability in nursing practice to provide the best care to the patients (Hanucharurnkul, 1997).

The major element of the care model derived in this study is composed of the phenomenon of family caregivers' participation in patient care. This phenomenon could be divided into 5 phases: desperately need for reliance, ready for participation, sharing of care, establishing self-efficacy before going home, and self-support. Promotion of family caregiver's participation in care includs providing care to patients and the family caregivers, and enhancing caring ability in both the patient and the families so that they can care for the patient at home. Strategies which nurses use to promote the family caregiver's participation in patient care can be a single method that can be used continuously from the beginning until the recovery period or a specific strategy for a specific period. In the meantime, passing through stress and anxiety also takes time so that the family caregivers have to try and learn in order to be able to care for the patient. Many have to rely on the guidance of the health care team and gradually learn to stand on their own. Trust and reliability, caring and compassion of the nurse, sharing information among family members and helping each other, caring experience, hope, reflection, support group, and the patient's recovery are the important related factors that influence the dependent care agency.

The findings in this study also revealed that the final model constructed in this study is similar to that of the tentative model derived from the pilot study. However, the model is better refined and more specific than the tentative model. The practicality of the model to the caring of the traumatic brain-injured patients comes from the wholehearted coordination between the family caregivers, nursing staff and other care providers. Without this continuous coordination on planning, action, observation, reflection, evaluation, and revision plan, this participatory action research could not have been finished.

The model constructed in this study is similar to the nursing system constructed by Songwatthana and others (2000). The model, based on the action research results, also concentrates on the family caregivers' participation on the caring of the neurosurgical patient. The model of Songwattana and others provides the policy on the support system to provide the sufficient knowledge on the caring according to capability, perception, and readiness of individual family caregivers. Communication and coordination are implemented to encourage the will and morality of the family caregivers to care for the patient. The manual and media are produced to develop the learning ability of the family caregivers as well as to form the support group.

A comparison of Orem's General Nursing Theory, which was used as the framework in this study, with the other action research (Hanucharurnkul, 1995; Keeratiyutawong, 1994; Nantachaipun, 1996; Polploy, et al., 1996; Wattana, 1997) revealed that most research studies emphasized the development of the self-care ability to care for the patient himself or herself. This type of model subscribes to the idea that the patient should be taught to exist in the middle of the pain they are encountering. However, the model for traumatic brain-injured patients concentrates on the development of dependent care agency, which are mainly the family caregivers. This attempt is meant to build the ability of the family caregiver to care for the patient since admission until discharge and through follow-up at home. The family caregivers' capabilities have direct impact on the development of the patient's recovery and self-reliance.

These findings were congruent with the findings of Hirunchunha (1998) who tried to draw the model for the caregivers of stroke patients at home. This model emphasized on the participation of the caregivers to care for the patient as well as caring for one own, with the sustainability of the caring quality provided. The difference between these two models is the difference of time to promote the dependent care agency. That of Hirunchunha emphasized the home based care strategies, but this model emphasizes the development of the family caregivers' abilities and participation while the patient is still in the hospital which reflectes the steps of coordination between the family caregivers, nursing team and other care providers. This process reflectes the time requirement to sustain the development and the support of the use of participatory action research together with the core knowledge in Orem's General Nursing Theory.

The model in this study also reflects the need for appropriate capability development and knowledge of the nurses and the family caregivers. This is meant to encourage the nurses to appropriately care for the patients on their own pace. This finding is similar to that of Orem (1995) who believed that providing appropriate skills for nurses, patients, and family caregivers is needed if we are to succeed. The experience of the three groups of the audience was still needed to cover the entire field using the trail. The information links between all concerned parties, together with negotiation techniques, are also.

The process of model development and related factors

The development of the model in this study has remodeled the nursing services system. The objectives and the structure of the nursing organization that was conducive to the participation of the family caregivers were implemented. The family caregivers were allowed to stay with the patient 24 hours. This measure facilitates the family caregivers to learn how to care with themselves and encourages the family caregivers to participate in patient care (Sharp, 1990; Suwanno, 1997). This adjustment involves the changing of the nurse's dominant care provider role to the partnership in the caring system and promotes the patients and families to take care of themselve. The total responsibility assignment, as well as the continuous attentive and sincere care provided by the nurse, could promote closer relationships between the nurse, other care providers, the family caregiver, and the patient. Trust and believe gained facilitate the effective cooperation, sharing of knowledge, and collaborative working skill which has great impact on the effectiveness of the family caregivers' participation and potential.

Promotion of the family caregivers' participation in care for the patient in order to develop the sustainable abilities of the patient and the family caregiver from the admission to the discharge period involves 5 strategic steps as follows:

1) **Providing care to the patient and the family caregiver.** As the accident happened so suddenly many family caregivers are unprepared to face the shock; therefore the "desperate need for reliance" to alleviate the burden is needed. The financial problems, the lawsuit, as well as the spiritual supports would be of great help. In this initial critical period, the family caregivers mostly are in the panic, blurred, and unable to think rationally. The only thought they could come up with is the wish for the patient to survive at this critical moment. Important support most needed in this period covers the condoling and the comforting measures to alleviate the pressure and anxiety of the family caregiver. Bringing back the sensibility facilitates the regaining of the caregivers' composer, which allows them to perform the normal activities and activities related to the patient.

Data obtained from this study revealed that trust and reliability, care and compassion that the family caregiver feel upon receiving the sincerity to serve from the nurse together with the information sharing among family members and helping each other promote the family caregivers' abilities. A warm atmosphere and a trustful relationship between relatives and nursing staff, as well as privacy and flexible visiting times, also promoted participation (Laitinen & Isola, 1996).

2) **Caregivers' ability development.** In passing to the second period, many family caregivers want, more or less, to get involved in the caring process. They could see the meaning and important of the participation in patient care to gain some hope and expectation of the patient's recovery. However, the usual problems most

caregivers have are the wish for the regaining of consciousness of the patient, lack of knowledge on how to provide proper care to the patient, and necessily to stop working in order to care for the patient. In response to these problems, the strategies used to promote the family caregiver's participation mainly concern with the preparation of the family caregivers. This process aims to make them realize the actual situation of the appropriate care, to acquire caring knowledge and skill, and most of all to gain enough confidence of their ability to care for the patients. The family caregivers would be taught how to perform the rehabilitation and complication prevention techniques. Thorough information should also be provided to facilitate the mutual goal setting of the care plan between nurses and the family caregivers. In so doing, nurses have to understand the pattern of lifestyle, responsibilities, and other specific limitations of individual caregivers. This baseline information would enable the nurse to perform the appropriate mutual goal setting with the individual caregiver. The knowledge and skill development as well as the mutual evaluation would empower the family caregiver. The family's involvement increases the readiness of the family caregiver and promotes the effectiveness of the family caregivers' participation. Family participation in the preparation phase benefits the family members as well. Learning about the caring strategies together prepares the other family members as a substitute caregiver if needed. This sharing of burden comforts the family caregiver's mind and builds sense of belonging, love and to be loved. Knowing that their devotions are recognized and receiving supports, in materials and services, could encourage the family caregiver to face and solve the problems and overcome the obstacles (Hanucharunkul, 1991).

Moreover, it has been found that the past experience is a valuable asset that facilitates the fast track learning and increases level of confidence in providing care to the patient. Hope also inspires the will to participate in the care and reflection process to crack the root of the problems and the reaching of the possible solutions, these findings are consistent with those of Hirunchunha (1998).

3) Self-care ability development of the patient and maintenance of the caring ability of the family caregivers. At this stage, the family's caregiver participation had increased considerably. All the family caregivers had seen the light of hope, although at a different level. They would try their best and do everything they could to cooperate for the recovery of the patient. Nevertheless, the recovery of the brain-injured patient usually takes time. In some cases, they faced some difficulties, which increased the mould of the problems to the already exist suffering. The promotion of strategies at this face therefore concentrated of the enhancement of caring abilities in both the patient and family. This would enable the family caregivers to organize their composer. The rehabilitation program for the patient would be implemented to alleviate the burden of the family caregivers. The patient's ability was to be restored by providing sufficient information and emotional support. Teaching, training, and increasing the level of participation would be conducive to the desired outcomes. Conducting mutual evaluation frequently and forming the support group would also increase the ability of reflection that is of the utmost benefit to the recovery of the patient.

The finding from this study revealed that the time that the family caregivers need to gain the competency and ability to organize is varied. It depends on the health status of the patient, help from the family, and the comfort from the support group.

The support group, in particular, plays an important role in maintaining the will of the family caregivers. The informal meeting allows many family caregivers who are suffering from the same fate to have a chance to share their shocks, sorrows, sufferings, and hope. The direct experience they have shared may shed some light on the others, and friendships developed could facilitate the support among the family caregivers, the health team and other support resources. The support group is proved to be an effective way that helps family in meeting their needs (Acorn, 1993; Campbell, 1988) and boosts up the caregiver's competency (Suwanno 1997). Moreover, most caregivers are satisfied with the impact of the support group (Songwathana, et al, 2000).

4) Building self-efficacy. This phase concerns the preparation of the patients and the family caregivers as well as establishing the self-efficacy in their mind. The patients and the family caregivers must be equipped with sufficient knowledge and skill, as well as solution to the common problems as the help from the nurse would no longer be available. The factors that assure the family caregivers of their competency are the caring experience earned in the hospital and the recovery of the patient. These findings was similar to the finding of Hirunchunha (1998) which found that the caring experience, as well as the patient recovery had great impact on the confidence of the family caregivers to provide home care.

5) Facilitating the transitional period. The follow-up on how the patient and the family caregiver go along the course of life is also crucial. This follow-up could be either by phone or home visit. The important factors that help the family caregiver to stand on their own are the support of the family members, the patients' recovery, and the nurse's follow-up. These factors empower the self-worthiness of the family caregivers knowing that they are the valuable assets to the patient and other family members.

Impacts of the model on participants' perception and satisfaction

The findings of the present research reflected the changes of the perception and the satisfaction among the nursing staff and the family caregivers as follows:

1. **Nursing staffs' perception and satisfaction with participation**

The research data revealed that the nurses perceived the benefits and value, and were satisfied with participation in care. Most of them were aware that this model was another milestone of nursing service development. The good relationship between the nurses and the family caregivers built trust and reliability that encouraged the free expression of idea and need. These enabled the nurses to provide active care according to the demand of the patient and the family caregivers. This benefited the heath status of the patient.

On the other hand, self-development of the family caregiver inspired the nurses to also develop themselves by means of group discussion. Through the meeting, the knowledge and experience could be exchanged. Breda and others (1997) found that weekly meetings of nurses facilitate the study and discussion. The study group allows the participants to learn from each other, to share their experiences, and to produce useful knowledge to them. Likewise, Wattana (1997) found that nurses are satisfied with the participatory care practice between nurses and clients. They realize that the patients' participation produce better frame of the services that answer the need of the clients. The quality of service has considerably increased and more satisfactorily served the clients needs. Continuos sincere care and attention from the nurses established the trust and confidence of the nurses in the client's mind. Thus, nurses gain acceptance from the clients and in turn this acceptance gives rise to the professional pride.

As far as the problem was concerned, it was found that the nurses were not so certain of their knowledge and skill to care for the brain-injured patients, as they perceived that the specific knowledge and expertise were required in order to provide effective care for this complicate situation. Moreover, they had already overloaded work which prevent them from fully participating in the activity.

2. The family caregivers' perception and satisfaction with participation

Data elicited from the study revealed that the family caregivers were satisfied with the participation in care that empowered them to get hold of the patient's fate and gave them a chance to provide attentive care for the patient. The family caregivers perceived that the nurses provided quality care, had extended friendship to the patient and the caregivers, and had good human relation, attentiveness, participation in caring. The good outcome was reflected in the patient's improvement. The quantitative data analysis revealed that the family caregivers had statistically significant better scores on the will to participate in the care, the participation, and the participation satisfaction after the participation took place.

The findings were in congruence with the study of Yamvong (1995) who found that application of the nursing theory to develop the care competency can increase the ability to perform the duty and the relationship system. Allowing the patient and the caregivers to participate in the caring process increases their satisfaction of the care received. Findings from various studies (Keeratiyutawong, 1994; Shawong, 1992; Wattana, 1997) have agreed that the participatory care forges the closer interaction between the nurses and the family caregiver, thus increases the level of satisfaction of the care received. The participation allows the family caregivers to learn and understand the actual situation. A chance to have hand-on training lessens the anxiety but increases the confidence to perform their duty. The acknowledgement as a team increases the self-worthiness of the caregiver which answers the hierarchy of need of the person (Arnantapunpong, 1995). Nevertheless, the findings of Intorn (1996) was different as she found that there was no significant different of the satisfaction toward the care received between the caregiver that was encouraged to participate in the caring and the caregiver that was not. However, the difference may be due to the limited number of sample and the untimely measurement of the satisfaction.

Impacts of the model on the patient's recovery

The evaluation of the effectiveness of the model towards the recovery of the patient was conducted by using the Modified Disability Rating Scale, with complication inventory tool and length of hospital stay as the evaluation indicators. The findings are as follows:

1. Modified Disability Rating Scale

The findings revealed that most traumatic brain-injured patients had statistically significant score of Modified Disability Rating Scale at the posttest higher than at the pretest period. The findings reflected the effectiveness of the family caregivers as significant support resources to the patient. The limitation of the patient was supplemented by the family caregiver. The patient could still have the appropriate care in correspondence to the specific phase which facilitated the fast recovery of the patient. These findings underlined the importance of the family and the caregiver to the brain-injured patients.

Data obtained from various studies revealed that the systematized rehabilitation by means of the mutisensory stimulation, assistance to the patient to perform daily activities, and the complication precautionary provided by the caregivers and the family accelerate the recovery of the patient (Cope & Hall, 1982; DeYoung & Grass, 1987; Jones, et al., 1994; Kater, 1989; Lewinn & Dimansescu, 1978; Mackay, et al., 1992; Morgan, et al., 1988 cited by Mackay, et al., 1992). However, the findings from Hall, Brandys and Yetman (1992) suggested that the mild brain-injured patients physically could recover at a short period of time after rehabilitation and 97 percent of the patients could return to their normal life (Tepahudee & Phuenpathom 1999).

2. Patients' complications

In this study, three severe brain-injured patients had complications during treatment. The complications found were inflicted by pneumonia, urinary tract infection, and pressure sore. One patient had the right hand contracture after participating in this research project and needed to continue the rehabilitation at home. The finding was consistent with the finding of Intorn (1996) who found that the group of patients with relatives' involvement had statistically significant fewer complications than the group with no relatives' involvement. Nevertheless, the finding of Arnantapunpong (1995) was different as she found that there was no significant different of the patients' complication between the group of patients with and with no relatives' involvement.

3. Length of hospital stay

As far as the lenght of hospital stay was concerned, it was found that the durations of stay in the hospital of the mild, moderate, and severe brain-injured patients were between 8-14 days, 9-36 days, and 14-148 days, respectively. The patient who had to stay in the hospital for 148 days suffered the complication from pneumonia, urinary tract infection, and pressure sore. These complication forced him to remain in the intensive care unit for 22 days. He had surgery for 4 times: Craniotomy to remove blood clot, V-P Shunt for hydrocephalus, Revised V-P Shunt after infection, and Harrington Rod instrumentation from delay diagnosis. The complications delayed the recovery of the patient, prolonged the length of hospital stay, and increased the medical cost up to 242,536.00 bath.

A review of a study conducted in 1997 (Potaya, 1999) revealed that the length of hospital stay for the mild, moderate, and severe brain-injured patients were 2-77 days, 5-81 days, and 7-168 days, respectively. The difference of the durations of these two studies may be explained by the effect of the family caregivers' participation in caring of the patients. The findings of Hall, Bandys and Yetman (1992) and Mackay and colleagues (1992) were similar to the findings of this research in that the systematized rehabilitation helps the recovery of the patient which in turn shortens the length of stay in the hospital of the patients.

As for the cost of the treatment, it was found that the cost varied according to the level of severity, between the average of 19,449.43, 19,467.43, and 68,999.17 baht for the mild, moderate, and severe cases, respectively. A review of the average family income of not more than 5,000 bath per month per patient and not more than 10,000 bath per month per family caregiver confirmed that these accidents had seriously affected the family, society and the nation at large.

Contributions to knowledge development

This nursing model has been drafted according to the situation-specific theory for the traumatic brain-injured patients who received treatment at the Bhumibol Adulyadej Hospital. Situation-specific theories are in congruence with the nature of nursing care and the goal to affect health care for specific populations. This type of theory allows us to reflect the diversity of clients and their voices and silences. They are based primarily on the explanation of responses, meaning, interpretations, abilities, and goals through multiple sources of data, experience, methodologies, and philosophies (Meleis, 1998). The model in this study was constructed based on Orem's General Nuring Theory (1995) experimented and applied to actual use in the natural setting. This attempt could be seen as the last phase of knowledge development according to the knowledge development period posited by Orem. According to her, the nursing science is the science of the practitioner. Therefore, the knowledge development is necessary to begin with the forming of the broad conceptual framework and end with the practical knowledge to provide the specific care to specific group of clients. The findings support the application of the nursing science knowledge of Orem to integrate with the participatory action research. This integration is corresponded to the various phases of care (critical analysis, decision making, practice, and monitoring) and the research problem solving (evaluation of the situation, planning for the solution, practice, inspection and evaluation)

This empirically substantiated Orem's General Nursing Theory (1995) which explains that the dependent care agency can learn and apply knowledge, enables to promote well being to the patients. The finding revealed the stage of development of family caregivers' abilities in the collaborative care situations. It also consolidated the benefits of promotion family caregiver's participation in patient care. The dependent care is an essential concept that nurse should be acquired to encourage the family members abilities for participation in patient care.

The lessons learned

Conducting the research gave the investigator first hand experience from the beginning of analyzing the problem, entering the field setting, starting the project until finalizing the findings. This lesson was proved to be valuable in three following ways:

1. The lesson from conducting the participatory action research

Coming to the setting in this study which was the Neurosurgical Ward to observe the situations and problems of the brain-injured patients made the investigator realize that providing care to this group of patients was a complicate phenomenon mixed with several interrelated factors. The caring tradition implementation of was monopolized in the hand of the health care providers. The reason for failure of the caregivers' participation implementation lied in the fact that the power to plan and decide the caring was not allocated to the other resources such as the family care givers. The problem lingered until the patient was discharged from the hospital. Therefore, the caring and rehabilitation for the patient at home was not properly executed due to lack of knowledge and skill of the caregivers and the family members.

Personally, the investigator truly believe in individuals' potential to perform any task that they are given a chance and are trained to do. The hand-on experience gained during the implementation of the family caregivers' anticipation model makes the investigator realize the spirit of teamwork. With team and the multidiscipline cooperation, the success lies in the hands of the members of the team. Therefore, the family caregivers' participation is an effective strategy that nurses should encourage. This coordination and encouragement should be the major role of the nurse to link all the possible resources to partake in this brave journey to save the life of the suffered patients.

Conducting this qualitative participatory research with the complicate cases was not an easy task. Various limitations were clearly seen as early as the starting point. The investigator's skill to carry out a qualitative study, budget, the time, and many others did not undermine the will to track along this challenging road of conducting participatory action research.

Tracking along the first corner of the winding road to help improve the quality of care for the traumatic brain-injured patients, the investigator put wholehearted effort to encourage the family caregivers' participation assuming that the other nurses would share the same belief. This overbalances the other end of the continuum. Many times the investigator decided or performed several functions without consulting the staff nurse. The uneasiness was felt among some staff members. Nevertheless, the process of the participatory action research that included mutual reflection, evaluation, and adjustment of the care plan among the concerned parties—the investigator, the nursing staff, and the family caregivers—revealed that things could not be easily implemented as originally planned. Limited number of staff, work overload, etc., could influence the achievement of the goal. At times, plans had to be reconsidered and redrawn.

Besides, the investigator lacked an experience in analyzing the mountain of qualitative data. The problems of the data interpretation seemed to be bigger and bigger. However, suggestions from friends, colleagues, advisors, and others shed light to the end of the tunnel. The success could not be achieved without the reflection process through which the body of knowledge could gradually accumulate. The inspiration that happened to the investigator soared up to the peak as the quality of the participatory care provided to the patient proved to be an effective and efficient measure. The patients and the family caregivers learned to stand on their own, the duration of hospital stay was shortened, the patient's complication was also rare, and most important of all the medical cost decreased. The pride of the profession was clearly acknowledged. Where there is a will, there is a way. The outcomes of this research definitely not only benefit the patients but also all others as well as the body of nursing science knowledge.

2. The lesson to the investigator's self development

The inspiration to conduct the participatory action research came from the realization of the limitation in performing daily clinical works. Implementing the theoretical knowledge in the clinics to practical practices was such a challenge to the limitations that the investigator had. Coming to the critical period taught valuable striving experiences to the investigater. The supports from all resources enabled the investigator to brave to the ups and downs and could finally successfully pass all the sufferings. The reflective process taught the investigator to become highly patient, endure and hold on to the determination to solve the problems and overcome the obstacles.

3. The lesson for the development of nursing science knowledge

The nursing science knowledge gained from this study reflects the need to apply the participatory action research into actual practice to develop the practical knowledge and the clinical nursing practice. This new "participatory" approach can replace the traditional model that emphasizes the content and the nursing process patterned after the biomedical model emphasizing the professional ability to solve the problems. Moreover, the knowledge gained in this study facilitates the development of the specific care to particular patients according to the context of the present society. It takes into consideration the environmental factors, belief, and the lifestyle of the people that have great impact on the individual health care and the dependent person.

CHAPTER VI

CONCLUSION

The conclusion of this study is presented in two parts as follows: summary of the study, and implications and recommendations for future research.

Summary of the study

This participatory action research aimed to develop the model for family caregivers' participation in caring for traumatic brain injured patients in the hospital. Specifically, the research intended to describe the process of model development, to explore influencing factors on collaborative process, to determine the impact of the model on participants' perception and satisfaction with participation and on the patients' recovery, and to explore the impacts of the model on other care providers. The participants of 30 nursing staff, 22 caregivers and 20 brain-injured patients were recruited according to the predetermined criteria. The study was implemented during April 2000 to March 2001 in the Neurosurgical ward, Bhumibol Adulyadej Hospital, Bangkok.

The research instruments comprised of 2 manuals and a patient assessment form. The manual included the Nursing Manual for Promotion of Family Caregivers Participation in Caring for Traumatic Brain-injured Patients and the Rehabilitation Manual for Family Caregivers of Traumatic Brain-injured Patients. The investigator originally constructed the manuals while the patient assessment form was translated into Thai from the Ranchos Los Amigos Levels of Cognitive Functioning Scale (LCFS).

Five sets of instrument were used to collect the data, including: 1) The General Information Questionnaire; 2) The Family Caregivers Preference, Actual Participation and Satisfaction with Participation in Patient Care Questionnaire; 3) The Interview Guide of the Participant Perceptions; 4) The Participatory Process Evaluation; and 5) The Patient Recovery Assessment Tool included Modified Disability Rating Scale which was the combination of the Disability Rating Scale and the Functional Independence Measure (FIM), and The Complication Inventory.

The research process was divided into 4 phases: the preparation phase, the action phase, the evaluation phase, and model development. The preparation phase began with a thorough analysis of the current clinical nursing as well as the related environment. The in-depth interview, the participant observation and informal dicussion were used together with the patient's retrospective background information. The data gathered through these strategies were used as the baseline data for constructing the research instruments and for later comparison to evaluate the intervention outcomes. The investigator and the key informants conducted 3 case studies to arrive at the tentative care model which was implemented in the action phase. In this phase, the qualitative data collection strategies were used to facilitate data gathering. It included in-depth interviews, field notes and group seminars. A tape recorder and a camera were used to record the relevant data. The action research cycle implemented included 4 steps: planning, action and observation, reflection, and revision of the plan. The core concept and explanation elements were extracted from the research data after data analysis was performed and the findings were interpreted in the evaluation phase. Finally, model development, the phase of concluding the process and outcomes of the study and testing for validity was carried out.

Summary of the findings

1. The characteristics of the participants

The findings revealed that the nursing staff comprised of registered nurses, technical nurses and nurse aids with an average age of 29 years. Eighteen of them had worked in this unit for 1-3 years and only eight persons had worked here for more than 5 years.

The family caregivers were mostly females, being either spouses or parents of the patient, working as trader or being self employed. They had an average age of 36.5 year with the income less than 10,000 baht per month. Most of them had experience in caring for the sick person, and also had the assistant who could substitute as a caregiver while the patient was still in the hospital.

Finally, most of the brain-injured patients aged between 20-39 years, were single, finished secondary school, and working as an employee. Most of them had motorcycle accidents which caused severe, moderate, and mild brain injuries.

2. The model for family caregivers' participation in caring for traumatic brain injured patients comprised of 4 elements: the phenomenon of family caregivers' participation inpatient care; the promotion family caregiver participation in care, factors influencing the dependent care agency, and the care outcomes.

The phenomenon of family caregivers' participation in patient care included 5 phases of action. The first phase "Desperate need for reliance" included the need for helper, financial support, lawsuit advisor, and spiritual support. The second phase " Readiness for participation" built up the courage to care for the patient which concerned the reasoning of love and care, duty and responsibility, and understanding of the participatory care and its expectation. In the third phase "Sharing of care," the family caregivers experienced various situations such as confusion, exhausion, and depression, etc. Upon reaching the fourth phase, the patient had passed the critical period, gained recovery and were well enough to be discharged. Therefore, this period, "Establishing self-efficacy before going home," aimed to establish the self-efficacy of the family caregiver to continue the care at home. The final phase "Self-support" was taken place when the family caregiver was equipped with the will, the skill, and ability to provide care at home. This phase also included the follow-up after the discharge.

As regards the promotion of family caregivers' participation in care, several measures were provided to encourage and prepare the family caregivers for the participation in care. It included providing care to the patient and the family caregiver, caregivers' ability development, self-care ability development of the patient and maintenance of the caring ability of the family caregiver, building self-efficacy, and facilitating the transitional period. The nursing staff and other care providers provided wholly and partly compensatory and educative supportive nursing system that allowed the family caregivers to have gradual understanding and gain the ability to do the care needed. To be able to perform the care properly, the family caregiver needed certain time, endeavor, and learning ability.

Not only the family caregiver's adaptation but also the nurses' adaptation were required in the participation process, which emphasized the participation and the empowerment of the family caregivers in the process. Nurses' attitudes must be modified to positively accept the core concept of the model and retrained them to have the desired nursing practice. Five strategies were used to improve the nurse's caring attitude and behavior—reflecting on quality of care, providing information and knowledge, role modeling, providing support and reinforcement.

Factors influencing the dependent care agency included trust and reliability, caring and compassion of the nurses, sharing of information among family members and helping each other, caring experience, hope, reflection, support group and the patient's recovery.

3. **The impacts of the model** Several positive outcomes appeared as follows:

3.1 The perception and the satisfaction of the participants was positive. Most of the nursing staff realized that this model could promote efficiency in the nursing services, lead to self-development, enhance family caregiver's abilities, and make them proud of themselves and profession. The difficulties during the implementation of the model were lack of confidence in the knowledge and skills in caring for the brain-injured patients, and heavy workload that prevented them from providing maximum care. However, the positive perception increased the level of satisfaction of the family caregivers as they were satisfied with the caring behavior of the nurses, and the chance to participate in patient care and the patient outcome.

3.2 The recovery level of patients who received the participatory caring model in the predischarge period was statistically significantly higher than that in the admission period. However, three severe brain-injured patients had complications that prolonged the stay in the hospital and therefore increased the medical expenditure of the patients.

3.3 Impacts of the model on the other care providers. Positively, the sharing of information and increasing level of family caregivers' involvement in decision by the neuro-surgeon facilitated the fast recovery of the patient. However, this change of practices forced the physician to partially alter the service system and the learning and teaching system. The family caregivers were acknowledged and they played an important role in the investigation process. The decision concerning the care plan must be mutually executed. This alteration also happened in the work process of the physiatrist and the physical therapist who had to additionally provide the consultation, suggestion, teaching and training session concerning the rehabilitation technique to the caregiver. The social worker also had to allocate more time to tend to the need of the family caregiver.

Implications and recommendations

The model for family caregivers' participation in caring for traumatic brain injured patients was drawn based on the data collected in the Neurosurgical ward of the Bumibol Adulyadej Hospital. Therefore, the generalization of the results might be limited. The difference of settings such as structure, policy, and management system as well as the participant qualifications could effect the implementation of the model. The following suggestions may be useful to maximize the utilization of the model:

1. **Implication to nursing practice**

1.1 Nursing service system management Policies concerning the encouragement of the participation of the family caregiver in providing care to the patient in the ward should be clearly stated to facilitate the quality of the patient care. Nurses will play an important role in evaluating the readiness of the family caregiver to participate in the care process. The preparation of the family caregiver as well as the setting up of the environment that is conducive to the caregivers' participation could be well taken care of by the nurse. An appropriate nursing system should include the beginning of the admission, evaluation of the practice, continuous support until the follow-up at home after the discharge from the hospital. The effective coordination and referral system should also be set up.

1.2 Clinical nurse specialist The findings from this study have suggested that the nurses who are qualified to implement the model are clinical nurse specialists. It is then recommended that in this situation there should be at least one clinical nurse specialist who possesses a graduate degree in nursing. She is a key factor to maintain the effectiveness and sustainability of the model. The clinical nurse specialist is well-prepared to provide comprehensive care and illness management for the brain-injured patient and the family caregiver. She will not only provide the direct care to the patient and family but also provide consultation and teaching for staff development as well as conduct a research utilization in this area. The clinical nurse specialist must be able to provide the advice and suggestion, interpret and apply the research result to the practice, and execute the sound decision to solve the problem. Additionally, she can work with nursing peers, physicians and other care providers in expanded collaborative relationships. These practices are expected to increase the quality of care.

1.3 Organizing the workshop This workshop could facilitate the modification of the service-oriented attitudes among the nursing staff. The attitudes toward the provision of the service to the patient and the family caregivers should be redirected. The patient and the family caregivers should no longer be viewed as the passive recipient of nursing service but the colleague whose role in providing care to the patient is equal to the nurse's role. The activities and practices relevant to the caring system should also be adjusted according to the family caregivers' participation concept.

1.4 The manuals Two manuals, one for the nurse and the other for the family caregivers, were developed as a result of this study to provide the detailed guidelines, strategies, and steps to be taken in performing various participatory cares and rehabilitation practices to the patient at different stages. These manuals are useful for the nurses and the family caregivers as they could easily follow and practice the instructions step by step.

1.5 The use of self-help group or support group The non-formal encouragement in the form of the self-help group or support group seems to be a better approach to develop the family caregivers' abilities. The relaxing environment in which no rules or regulations are imposed is conducive to a free flow of information exchange that facilitates the knowledge and experience acquisition and reinforces the close relationship among the members of the support group. Knowing that there are others who also suffer from the same fate could boost the will and motivation of the family caregivers to fight the hardship of the caring and strive for the patient's survival. The effectiveness of the support group lies on the nurse's ability to organize the group. The nurse must be sensitive to the information. Knowing all members very well also enables the nurse to facilitate the interesting topics during the discussion. The effective meeting for the support group should not be long and it should discuss only one or two topics at a time. However, the discussion should dig deep to the root of the problem. This scrutiny could help the family caregiver to learn more. Participating in the discussion and contribution could also give rise to the pride and self-worthiness of the family caregivers.

1.6 The use of telephone contact The call made after the patient has been discharged is a valuable and low cost measure that reflects the quality of the nursing intervention. The calls allow the nursig staff and the family caregivers to mutually share the information needed during this transition period. Sufficient and clear information could build the confidence and motivate the family caregivers to continue the quality and appropriate care at home.

1.7 The referral coordination between the concerned unit Providing home visits to some patients may require the referral contact with the staff from the local health care center. In this case, close coordination with this unit should be useful in providing home care to the patient as the local health team could provide immediate treatment if needed.

2. Implications for health care reform

The findings of the study have suggested that implementation of the model for family caregivers' participation in caring for traumatic brain injured patients needs concerted efforts from all concerned administrative units as well as a radical change in the administrative work. The nurse administration should facilitate the reshuffling of the related policies, service systems, adequate staffing, appropriate workload allocation, and training as well as adequate budget to improve the environment hospital wide. The visiting policy may be revised to allow longer duration or higher frequency of the visit. The family caregiver should be allowed to collaboratively work with the nurse in the ward. Review of the shift, redistribution of the workload and curtailing some of the unnecessary steps in the process might be of help to reduce the burden of the nursing staff. Support documents and printed media to communicate with the patients should also be prepared to support the follow-up and home-visit. Moreover, the nursing development program should be implemented to increase the nursing staff competency and effectiveness. Finally, the nurse administrator should pay more attention to and encourage the morale among the nursing staff.

3. Implication to inservice education

Although the concept of the patient's and the family caregivers' participation has been acknowledged, the practice guidelines and the direction have not been explicitly discussed. Nursing intervention in many hospitals still put more emphasis on the practical intervention derived from the bio-medical model. Therefore, special courses on the promotion strategies of patient and family participation in care as well as the specialized advanced practice for the brain-injured patients should be conducted among the nurses. This continuing education is expected to facilitate the realization of the family caregiver's power in the care process, and the widely accepted essence of the participatory care could sustain the application of the model.

4. Implications for standardization of nursing practices

The results derived in this study could be used as a basis for the designing the ready-made Clinical Practice Guideline, Outcome Management, Outcome Indicators, Cost-effective Care as well as Standard Care Package for the brain-injured patients. The above information could facilitate the Clinical Pathway/CareMap of the standard procedures that could further facilitate the fast track and effective service in the clinical practice.

5. Implications for safety precaution measures

The geographical data and the data related to traumatic brain injury have revealed that the traumatic brain injury is likely to occur with the adolescent and the late adolescent males. The major cause of accident is from motorcycles, and this can be prevented if the drivers would pay more attention to the safety rules and regulations.

The weak law enforcement escalates the severity of the problems. Although the driving law that requires all the motorcycle drivers and passengers to wear a safety helmet has been imposed since 1995, various obstacles arise as this law has never been seriously and strictly enforced. The statistics of the patients from motorcycle accidents was temporally lowered during the enforcement period of the law. Therefore, new strategies raising awareness of the adolescents and society, and enhance adequate/safe public transportation system is needed. The behavior modification on safety driving should also be seriously implemented. The concept of safety-conscious should be emphasized among the students since high school. A pocketbook on traumatic brain injury scenario to encourage layman to be concerned with the impacts of traumatic injury should be applied. In addition, the media campaigns to encourage the driver to observe all the driving law should be launched. Driving and motor vehicles law enforcement should be strengthened as well. The engineering aspect of the vehicles should also be taken into consideration of the common drivers and the official government alike. Finally, the safety equipment on the road should be fixed to improve the accident-prone areas.

Recommendation for further study

1. **Research methodology** More participaytory action research should be carried out to develop the care model in order to achieve practical knowledge that is the ultimate goal of the nursing science.

2. **The brain-injured patient research**

2.1 Limitation on budget and time may undermine the data gathered in this study. Collecting qualitative data on the sensitive area from seriously ill patients was not an easy task especially when there was no assistant to share the work load.

Therefore, these factors should be taken into consideration when a new research project is being planned.

1.2 The scope of the research should be extended to investigate the whole episode of the incident. The investigation of the before and after traumatic brain injury phenomenon which includes the management of the rescue team, the patient's transfer, the multidisciplinary care model, the follow-up research of the lifestyle of the patient at home, the outcome of long term care after discharge, and the health promotion and injury prevention, etc. would compliment the holistic view of the brain-injured patients and increase understanding of this particular group of patients.

3. The research on the family caregivers' participation should be extended to cover other chronic illnesses or disabilities of patients who also need care and rehabilitation from the nurse and family caregivers such as the patients who suffer from stroke, spinal injury, etc. Thus, better nursing intervention, which responds to specific needs of particular patients, could be drawn and the better able caregivers could be achieved.

4. Cost-effective care of the patient and economic value of the family caregivers' participation model should be studied both at the hospital and at home during the follow-up period.

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APPENDIX A

LIST OF EXPERTS

Six experts were consulted concerning content validity assessment of family caregiver preference, actual participation and satisfaction with participation in patient care questionnaires and an interviewing guide of participant perceptions.

They were:

1. Assoc. Prof. Prakong Intarasombat, M.Ed.(Nursing Administration)
   Ramathibodi Department and School of Nursing
   Faculty of Medicine, Ramathibodi Hospital, Mahidol University.

2. Assoc. Prof. Dr. Saipin Gasemgitvatana, D.N.S.
   Department of Surgical Nursing
   Faculty of Nursing, Mahidol University.

3. Lect. Dr. Atirat Wattanapailin, Ed.D.(Curriculum Research and Development)
   Department of Mental Health and Psychiatric Nursing
   Faculty of Nursing, Mahidol University.

4. Lect. Dr. Chanokporn Hanchanchaikul, Ph.D.(Adult Nursing)
   Faculty of Nursing, Chulalongkorn University.

5. Lect. Dr. Jiraporn Kespichayawattana, Ph.D.(Gerontological Nursing)
   Faculty of Nursing, Chulalongkorn University.

6. Lect. Dr. Sudsiri Hirunchunha, D.N.S.
   Department of Surgical Nursing,
   Faculty of Nursing, Prince of Songkla University.

Six experts and a back translator were consulted concerning content validity assessment of Rancho Los Amigos Scale, and Patient Recovery Assessment Tool.

They were:

1. Asst. Prof. Voravut Chanyavanich, M.D., Amer.Board of Neurosurgery.
   Department of Surgery
   Siriraj Hospital, Faculty of Medicine, Mahidol University.

2. Gp.Capt. Suchin Boonma, M.D., Thai Board of Neurosurgery.
   Department of Surgery
   Bhumibol Adulyadej Hospital, Royal Thai Air Force.

3. Wg.Cdr. Tanasotti Tumakul, M.D., Thai Board of Infectious Disease.
   Department of Medicine
   Bhumibol Adulyadej Hospital, Royal Thai Air Force.

4. Wg.Cdr. Wannapa Lertprapamongkol, M.D., Thai Board of Physiatrist.
   Department of Physical Medicine and Rehabilitation
   Bhumibol Adulyadej Hospital, Royal Thai Air Force.

5. Maj. Sumalee Suethanapornkul, M.D., Thai Board of Physiatrist.
   Rehabilitation Medicine Department
   Phramongkutklao Army Hospital.

6. Mrs. Uraiwan Taerungruang, M.N.
   Department of Nursing Service
   Siriraj Hospital, Faculty of Medicine, Mahidol University.

7. Asst. Prof. Dr.Orapan Thosingha, D.N.S.
   Department of Surgical Nursing
   Faculty of Nursing, Mahidol University.

APPENDIX B

INFORM CONSENT SHEET

คำชี้แจงเกี่ยวกับโครงการวิจัย และพิทักษ์สิทธิ์ของผู้มีส่วนร่วมในการศึกษา

สวัสดีคะ ดิฉัน นาวาอากาศตรีหญิงโสพรรณ โพทะยะ นักศึกษาหลักสูตรพยาบาลศาสตรดุษฎีบัณฑิต คณะพยาบาลศาสตร์ มหาวิทยาลัยมหิดล กำลังศึกษาวิจัยเรื่อง "รูปแบบการพยาบาลโดยให้ญาติผู้ดูแลมีส่วนร่วมในการดูแลผู้ป่วยบาดเจ็บที่สมอง" เพื่อพัฒนารูปแบบการพยาบาลที่เหมาะสม สนองความต้องการของผู้ป่วยและครอบครัว และสามารถนำไปปฏิบัติได้อย่างแท้จริง

ในการเข้าร่วมโครงการวิจัย ญาติผู้ดูแลจะมีส่วนร่วมในการปฏิบัติดังนี้

1. ให้ข้อมูลที่เป็นประโยชน์ โดยครั้งแรกจะเป็นการสัมภาษณ์การรับรู้เกี่ยวกับการมีส่วนร่วมในการดูแลผู้ป่วยบาดเจ็บที่สมองขณะรับการรักษาในโรงพยาบาล การสอบถามข้อมูลส่วนบุคคล ความต้องการมีส่วนร่วม การได้มีส่วนร่วม และความพึงพอใจต่อการมีส่วนร่วมโดยใช้แบบสอบถาม ซึ่งใช้เวลาประมาณ 30-60 นาที
2. ร่วมกับบุคลากรทีมสุขภาพ ในการประเมินปัญหา สถานการณ์ การหาวิธีการแก้ไข ตัดสินใจ และวางแผนการปฏิบัติดูแลผู้ป่วย โดยการประชุมกลุ่ม สัปดาห์ละ 1 ครั้ง และลงมือปฏิบัติตามข้อตกลง
3. เพื่อตรวจสอบการปฏิบัติ และประเมินผลการพัฒนารูปแบบ ญาติผู้ดูแลจะตอบแบบสอบถามเกี่ยวกับความต้องการ การมีส่วนร่วม และความพึงพอใจต่อการมีส่วนร่วมดูแลผู้ป่วยบาดเจ็บที่สมองอีกครั้ง ก่อนผู้ป่วยจำหน่ายจากโรงพยาบาล

ในกระบวนการพัฒนารูปแบบครั้งนี้ ดิฉันขออนุญาตบันทึกเทประหว่างการสัมภาษณ์หรือประชุมกลุ่ม และถ่ายภาพบางครั้งเพื่อประกอบการศึกษา โดยจะให้ท่านพิจารณาก่อนนำไปใช้

หากท่านมีข้อสงสัยประการใดเกี่ยวกับการศึกษาครั้งนี้ ดิฉันยินดีให้ความกระจ่างเพิ่มเติม ท่านมีสิทธิที่จะตอบรับหรือปฏิเสธการเข้าร่วมในการศึกษา และถึงแม้ว่าท่านได้เข้าร่วมในการศึกษาแล้ว ท่านก็มีสิทธิที่จะยกเลิกได้ตลอดเวลาตามที่ท่านต้องการ โดยไม่มีผลกระทบใดๆ ต่อการรักษาพยาบาล หรือบริการต่างๆ ที่ท่านและผู้ป่วยจะได้รับ

ขอขอบคุณในความร่วมมือ

นาวาอากาศตรีหญิงโสพรรณ โพทะยะ

สำหรับผู้มีส่วนร่วมในการศึกษา

ข้าพเจ้าได้รับคำชี้แจงตามรายละเอียดข้างต้น เข้าใจจุดประสงค์ในการวิจัยครั้งนี้แล้ว และเข้าใจว่าการวิจัยครั้งนี้ ข้าพเจ้าต้องให้สัมภาษณ์และให้บันทึกเทประหว่างการสัมภาษณ์และประชุมกลุ่ม รวมทั้งตอบแบบสอบถาม และปฏิบัติตามข้อตกลงของกลุ่ม ข้าพเจ้ายินดีเข้าร่วมในการศึกษาครั้งนี้

ลงชื่อ..

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APPENDIX C

GENERAL INFORMATION QUESTIONNAIRE

1. แบบสอบถาม ข้อมูลพื้นฐานบุคลากรทีมการพยาบาล

คำชี้แจง กรุณาตอบแบบสอบถามเกี่ยวกับตัวท่าน โดยเติมคำลงในช่องว่าง หรือทำเครื่องหมาย ✓ หน้าข้อความที่ตรงกับตัวท่าน

1. ท่านเป็น [ ] พยาบาลวิชาชีพ [ ] พยาบาลระดับต้น [ ] อื่นๆ ระบุ........................

2. เพศ [ ] ชาย [ ] หญิง

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7. ประสบการณ์การทำงานในหอผู้ป่วยศัลยกรรมประสาท............ปี

8. รายได้เฉลี่ยต่อเดือน........................บาท [ ] พอใช้ [ ] มีเงินออม [ ] มีหนี้สิน

2. แบบสอบถาม ข้อมูลพื้นฐานญาติผู้ดูแล

คำชี้แจง กรุณาตอบแบบสอบถามเกี่ยวกับตัวท่าน โดยเติมคำลงในช่องว่าง หรือทำเครื่องหมาย ✓ หน้าข้อความที่ตรงกับตัวท่าน

1. เพศ [ ] ชาย [ ] หญิง

2. อายุ ....ปี

3. ระดับการศึกษา [ ] ไม่ได้เรียน [ ] ประถมศึกษา
[ ] มัธยมศึกษา [ ] ประกาศนียบัตร
[ ] ปริญญาตรี [ ] สูงกว่าปริญญาตรี

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15. ปัจจุบันท่านพักอาศัยอยู่ที่ ....

ใช้เวลาเดินทางไป-กลับ ระหว่างบ้านพักและโรงพยาบาล.................ชั่วโมง / วัน

3. แบบบันทึกข้อมูลผู้ป่วยบาดเจ็บที่สมอง

ผู้ป่วยรายที่......... HN.................... AN ....วันที่.... เดือน............พ.ศ ....

ชื่อ............................นามสกุล................................. เพศ............... อายุ......... ปี

สถานภาพสมรส............ ศาสนา............ระดับการศึกษา.................อาชีพ.....................

รายได้ (ก่อนเจ็บป่วย) .... รายได้ (ขณะเจ็บป่วย).................................

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การเกิดภาวะแทรกซ้อน

1. การติดเชื้อในระบบทางเดินหายใจ

( ) ไม่เกิด

( ) เกิด ระยะเวลาหลังจากรับไว้ในการศึกษานาน ....วัน

2. การติดเชื้อในระบบทางเดินปัสสาวะ

( ) ไม่เกิด

( ) เกิด ระยะเวลาหลังจากรับไว้ในการศึกษานาน ....วัน

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5. อื่นๆ

( ) ไม่เกิด

( ) เกิด .... ระยะเวลาหลังจากรับไว้ในการศึกษานาน ......วัน

APPENDIX D

FAMILY CAREGIVERS PREFERENCE, ACTUAL PARTICIPATION AND SATISFACTION WITH PARTICIPATION IN PATIENT CARE QUESTIONNAIRE

แบบสอบถาม ความต้องการมีส่วนร่วม การได้มีส่วนร่วม และความพึงพอใจของญาติผู้ดูแล ต่อการมีส่วนร่วมดูแลผู้ป่วยบาดเจ็บที่สมอง

คำชี้แจง :

ข้อความต่อไปนี้ เป็นกิจกรรมการมีส่วนร่วมในการดูแลผู้ป่วยบาดเจ็บที่สมอง ขณะรับการรักษาในโรงพยาบาล ซึ่งในแต่ละข้อ จะมีช่องคำตอบเกี่ยวกับระดับความต้องการ การได้ปฏิบัติจริง และระดับความพึงพอใจต่อการมีส่วนร่วมในการปฏิบัติกิจกรรมดังกล่าว ใน 4 ระดับ คือ มาก ปานกลาง น้อย และ ไม่ต้องการ / ไม่ได้ปฏิบัติ / ไม่พึงพอใจ

โปรดอ่านข้อความทางซ้ายมือทีละข้อ แล้วพิจารณาว่าท่านต้องการมีส่วนร่วมในกิจกรรมนั้นหรือไม่ และมากน้อยเพียงไร โดยทำเครื่องหมาย ✓ ลงในช่องระดับความต้องการที่ตรงกับความรู้สึกของท่านมากที่สุด จากนั้นพิจารณาว่าท่านได้ปฏิบัติกิจกรรมหรือมีส่วนร่วมในกิจกรรมที่ต้องการนั้นมากน้อยเพียงใดในการดูแลผู้ป่วยที่ผ่านมาจนถึงขณะนี้ แล้วทำเครื่องหมาย ✓ ลงในช่องการปฏิบัติที่เป็นจริง ให้ตรงกับความเป็นจริงมากที่สุด และจากการมีส่วนร่วมในการปฏิบัติกิจกรรมดังกล่าว ทำให้ท่านมีความรู้สึกพึงพอใจต่อการปฏิบัตินั้นหรือไม่ และมากน้อยเพียงไร แล้วใส่เครื่องหมาย ✓ ลงในช่องระดับความพึงพอใจทางขวามือที่ตรงกับความรู้สึกของท่านมากที่สุด

APPENDIX E

AN INTERVIEW GUIDE OF PARTICIPANT PERCEPTIONS

1. แนวคำถามที่ใช้ในการสัมภาณ์การรับรู้ของบุคสากรทีมพยาบาลเกี่ยวกับการมีส่วนร่วมดูแลผู้ป่วย

1. ท่านคิดอย่างไรกับการให้ญาติผู้ดูแลเข้ามามีส่วนร่วมดูแลผู้ป่วย
2. ญาติผู้ดูแลควรมีส่วนร่วมดูแลผู้ป่วยขณะอยู่โรงพยาบาลหรือไม่ เพราะอะไรท่านจึงคิดเช่นนั้น

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5. ญาติผู้ดูแลและพยาบาลจะร่วมมือกันได้อย่างไร เพื่อดูแลผู้ป่วยให้ได้ประสิทธิภาพสูงสุด

2. แนวคำถามที่ใช้ในการสัมภาณ์การรับรู้ของญาติผู้ดูแลเกี่ยวกับการมีส่วนร่วมดูแลผู้ป่วย

1. คุณรู้สึกอย่างไรที่ผู้ป่วยต้องอยู่ในสภาพการเจ็บป่วยเช่นนี้
2. ขณะที่คุณเข้ามาเยี่ยมผู้ป่วย หากพยาบาลขอให้คุณเข้ามาดูแลผู้ป่วยร่วมกับพยาบาล คุณคิดว่าคุณทำได้หรือไม่
3. หากคุณได้มีโอกาสดูแลผู้ป่วยร่วมกับพยาบาล คุณคิดว่าคุณจะดูแลในเรื่องใดบ้าง

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13 การที่คุณได้มีโอกาสดูแลผู้ป่วยร่วมกับพยาบาล ตลอดระยะเวลาที่ผู้ป่วยรับการรักษาในโรงพยาบาลนั้น คุณรู้สึกอย่างไร (รู้สึกว่ามีประโยชน์ รู้สึกไม่สบายใจ รู้สึกกลัวบ้างหรือไม่)

APPENDIX F

RANCHOS LOS AMIGOS SCALE

Case no.....Name............................Age......yrs HN..................AN................Dx..............

Level	Cognitive functioning as demonstrated through behavior	Dates Tested		
I No response	a. complete absence of observable change in behavior when presented visual, auditory, or painful stimuli			
II Generalized response	a. demonstrates generalized reflex response to painful stimli b. responds to repeated auditory stimuli with increased or decreased activity c. responds to external stimuli with physiological changes			
VIII Purposeful-appropriate	a. alert, oriented; intact recall for past and recent events b. demonstrates carryover for new learning; functions independently, within physical capacities, once new tasks are learned c. able to formulate realistic goals for own future; may be candidate for vocational rehabilitation d. able to apply adequate judgment to daily living and community situations relative to premorbid ability level			

THAI TRANSLATION FORM

RANCHOS LOS AMIGOS SCALE

ผู้ป่วยรายที่...... ชื่อ..อายุ......ปี HN..............................AN.......................Dx........................

Level	พฤติกรรมที่ตอบสนองต่อสิ่งกระตุ้น	ผลการประเมิน		
1. ไม่มีการตอบสนอง	ก. ผู้ป่วยจะไม่แสดงพฤติกรรมใดๆ เพื่อตอบสนองต่อสิ่งกระตุ้นเลย ทั้งทางสายตา เสียง หรือ ความเจ็บปวด			
2. มีการตอบสนองทั่วไป	ก. มีการตอบสนองทั่วไปต่อการกระตุ้นที่ทำให้เกิดความเจ็บปวด ข. ตอบสนองต่อการกระตุ้นทางโสตประสาทซ้ำๆ โดยมีกิจกรรมที่เพิ่มขึ้นหรือลดลง ค. ตอบสนองต่อสิ่งกระตุ้นภายนอกด้วยการเปลี่ยนแปลงทางสรีระ			
8. การตอบสนองมีจุดมุ่งหมายและเหมาะสม	ก. ผู้ป่วยมีความตื่นตัว รับรู้ สามารถทบทวนความจำในอดีตและความจำในระยะสั้นได้ ข. สามารถเรียนรู้ การปฏิบัติกิจกรรมใหม่ เมื่อเรียนรู้แล้วก็สามารถทำเองได้โดยลำพัง เท่าที่ความสามารถทางร่างกายจะอำนวย ค. กำหนดเป้าหมายอนาคตของตนเองได้ และจะพัฒนาความสามารถสู่การฟื้นสภาพเพื่อการทำงานได้ ง. มีการตัดสินใจที่เป็นประโยชน์ และเพียงพอต่อการดำเนินชีวิตประจำวัน และสภาวะทางสังคมที่สัมพันธ์กับก่อนได้รับบาดเจ็บ			

APPENDIX G

PATIENT RECOVERY ASESSMENT TOOL

1. MODIFIED DISABILITY RATING SCALE

Case no……Name…………………………Age……yrs HN……………..AN……………Dx…………

Date/Time						
1. Glasgow Coma Scale		score				
Eyes open (C = eye closed by swelling)	Spontaneously	4				
	To speech	3				
	To pain	2				
	None	1				
Helper	Minimal assist (< 25%)	4				
	Moderate assist (25 - 50%)	3				
	Maximal assist (>50 - 75%)	2				
	Total assist (75 – 100%)	1				
Total DRS = 33 score						

THAI TRANSLATION FORM

MODIFIED DISABILITY RATING SCALE
(แบบประเมินระดับการสูญเสียสมรรถภาพของผู้ป่วยบาดเจ็บที่สมอง)

ผู้ป่วยรายที่ ………ชื่อ…………………………………………………………อายุ…………ปี HN………………………… Dx…………………………………

วันที่						
เวลา						
1. Glasgow Coma Score คะแนน						
การลืมตา สังเกตหนังตาบน (C = ตาบวมปิด)	ลืมตาได้เอง	4				
	ลืมตาเมื่อเรียก	3				
	ลืมตาเมื่อเจ็บ	2				
	ไม่ลืมตาเลย	1				
ต้องมีผู้ช่วยเหลือ	ทำได้แต่ต้องมีผู้ช่วยเหลือ < 25%	4				
	ทำได้แต่ต้องมีผู้ช่วยเหลือ 25 - 50%	3				
	ต้องมีผู้ช่วยเหลือ > 50 - 75%	2				
	ทำกิจกรรมเองไม่ได้เลย ต้องมีผู้ช่วยเหลือ 75 – 100%	1				
คะแนนรวมทั้งหมด = 33 คะแนน						

2. COMPLICATION INVENTORY TOOL

แบบประเมินภาวะแทรกซ้อนของผู้ป่วยบาดเจ็บที่สมอง

ชื่อ..................................อายุ........ปี HN.................... AN................ Dx....................

วันที่						
ผลการประเมิน	มี	ไม่มี	มี	ไม่มี	มี	ไม่มี
1. การติดเชื้อในระบบทางเดินหายใจ 1.1 ภาพรังสีปอดที่เกิดขึ้นใหม่มีลักษณะเป็นฝ้าขาว (infiltration) เป็นก้อนแข็ง (consolidation) เป็นโพรง (cavitation) หรือ มีน้ำคั่งในช่องเยื่อหุ้มปอด (pleural effusion) ร่วมกับ 1.2 มีอาการหรือสิ่งตรวจพบ 2 จาก 4 ข้อ ต่อไปนี้ - มีไข้ (T > 38 °C) - มีเสมหะจำนวนเพิ่มขึ้น และเปลี่ยนจากปกติ เป็นหนอง หรือ สีสนิม - ฟังปอดได้ยินเสียง crepitation และ/หรือ เสียงปอดเบากว่าปกติ - ปริมาณเม็ดเลือดขาวในเลือด > 10,000 cell/mm. (leukocytosis) โดยมีneutrophil > 80%						
4. ข้อติดแข็ง โดยการนับจำนวนข้อต่างๆ ที่ไม่สามารถเคลื่อนไหวได้อย่างเต็มที่ หรือ มีการเจ็บปวดเมื่อเคลื่อนไหว เช่น ข้อไหล่ ข้อศอก ข้อมือ ข้อเข่า ข้อเท้า						

APPENDIX H

THE MANUALS AND INFORMATION LEAFLET

1. Nursing Manual for Promotion Family Caregivers Participation in Caring for Traumatic brain injured patients

คู่มือพยาบาล "การให้ญาติผู้ดูแลมีส่วนร่วมในการดูแลผู้ป่วยบาดเจ็บที่สมอง"

สารบัญ

หน้า

2. Rehabilitation Manual for Family Caregivers of Traumatic Brain Injured Patients

คู่มือสำหรับญาติผู้ดูแล “การฟื้นฟูสมรรถภาพผู้ป่วยบาดเจ็บสมอง”

สารบัญ

หน้า

3. Information leaflet

เอกสารแนะนำญาติผู้ดูแล

อาการผิดปกติที่ควรสังเกตในผู้ป่วยบาดเจ็บที่สมอง

เมื่อผู้ป่วยกลับบ้าน ญาติควรสังเกตอาการผิดปกติทางระบบประสาทหรือภาวะแทรกซ้อนของผู้ป่วยที่อาจเกิดขึ้นได้ หากพบอาการผิดปกติดังกล่าวควรรีบนำผู้ป่วยมาพบแพทย์ทันที ซึ่งอาการผิดปกติที่พบอาจมีเพียงประการเดียวหรือหลายประการ ดังนี้

- ปวดศีรษะรุนแรงโดยไม่ทุเลา
- อาเจียนพุ่ง หรืออาเจียนติดต่อกันหลายๆ ครั้ง
- กระสับกระส่ายผิดปกติ
- พูดจาสับสนเลอะเลือน
- ง่วงซึมผิดปกติ ปลุกไม่ตื่น
- กำลังของแขนขาลดน้อยลงกว่าเดิม
- มีอาการกระตุกตามใบหน้า แขน ขา
- มีน้ำใสๆ ไหลออกมาจากรูจมูกหรือรูหู โดยไม่มีอาการเป็นหวัดนำ
- คอแข็ง
- ผิวหนังร้อน อุณหภูมิร่างกายสูงกว่า 37.8 C (ทางปาก)
- อาการอื่นๆ ซึ่งเป็นที่น่าสงสัย

หากท่านมีข้อสงสัยและ / หรือไม่แน่ใจเกี่ยวกับอาการของผู้ป่วยที่ท่านพบว่าสมควรต้องรีบนำผู้ป่วยมาพบแพทย์หรือไม่ หรือต้องการทราบรายละเอียดเพิ่มเติม สามารถโทรศัพท์สอบถามได้ที่:

❶ หอผู้ป่วยศัลยกรรมประสาท อาคารคุ้มเกล้าฯ ชั้น 6/1
โรงพยาบาลภูมิพลอดุลยเดช ☎ 0-2534-7611, 0-2534-7612 หรือ

❷ น.ต.หญิงรำเพย ชูโชติ ☎ 0-1763-6882

BIOGRAPHY

NAME	Squadron Leader Soparn Potaya
PLACE OF BIRTH	Chiangmai, Thailand
INSTITUTIONS ATTENDED	Mahidol University, 1981-1983: Bachelor of Nursing Mahidol University, 1986-1989: Master of Science (Nursing) Mahidol University, 1996-2001: Doctor of Nursing Science
FELLOWSHIP / RESEARCH GRANT	Doctoral Collaborative Program, Ministry of University Affairs, Thailand The Royal Thai Air Force
POSITION & OFFICE	1983-Present, Neurosurgical Intensive Care Unit, Bhumibol Adulyadej Hospital, Medical Directorate, Royal Thai Air Force. Bangkok, Thailand. Position: Staff Nurse.