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Evaluating Family Caregivers' Ability to Select Appropriate Care Techniques Following Discharge Instructions on Post Traumatic Brain Injury Symptoms

Connie J. Pardee
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EVALUATING FAMILY CAREGIVERS' ABILITY TO SELECT APPROPRIATE
CARE TECHNIQUES FOLLOWING DISCHARGE INSTRUCTIONS ON POST
TRAUMATIC BRAIN INJURY SYMPTOMS

By

Connie J. Pardee

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ABSTRACT

EVALUATING FAMILY CAREGIVERS' ABILITY TO SELECT APPROPRIATE CARE TECHNIQUES FOLLOWING DISCHARGE INSTRUCTIONS ON POST TRAUMATIC BRAIN INJURY SYMPTOMS

By

Connie J. Pardee

Post traumatic brain injury symptoms, including physical and cognitive dysfunction, and related behavioral changes, are present following minor to severe brain injury. These symptoms, especially cognitive dysfunction and behavioral changes, can be very stressful to family caregivers as they attempt to readjust after their loved one's brain injury. Nurses are in an ideal position to assist family caregivers with information on post traumatic brain injury symptoms and methods to cope with the symptoms.

This study evaluated family caregivers' ability to select appropriate caregiver actions following discharge instructions on post traumatic brain injury symptoms. A group comparison design was used. Subjects in the control group viewed videotaped discharge instructions on physical symptoms post traumatic brain injury. The experimental group viewed videotaped discharge instructions on physical symptoms, cognitive dysfunction and behavioral changes post traumatic brain injury. Both groups were given a written

post test after viewing the videotape. The means of the post test scores were compared using an unpaired t-test. Those who received information on physical symptoms, cognitive dysfunction, and behavioral changes had a higher mean score than those who recieved only information on physical changes. The hypothesis was supported that there was a significant increase ($p < .0001$) in family caregivers' ability to select appropriate caregiver actions for post traumatic brain injury symptoms by caregivers who received information on cognitive dysfunction and behavioral changes when compared to caregivers who did not receive this information.

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CHAPTER ONE

Introduction

The incidence of brain injury has risen with: 1) changes in the pace of our society, 2) more leisure time, 3) increased use of recreational vehicles, and 4) consumption of alcohol and drugs. The National Institutes of Health (1989) estimates that there are over 2 million traumatic brain injuries a year, with 500,000 severe enough to require hospitalization. A large percentage of these occur to 15 to 24 year old males as a result of motor vehicle crashes. Due to lingering disabilities from the brain injury, these individuals will potentially lose 40 years of gainful employment.

Brain injuries are classified on a continuum from minor to severe. Persons with severe traumatic brain injuries often exhibit physical and cognitive dysfunction post injury (Fisher, 1985; Grinspun, 1987; Tabaddor, Mattis, & Zazula, 1984; Warren, Goethe, & Peck, 1984). Persons with even moderate brain injuries experience some of the same symptoms (Rimel, Giordani, Barth, & Jane, 1982). Post traumatic symptoms of brain injury include somatic, psychophysiologic, and psychosocial parameters. These are manifested as headaches, dizziness, memory problems, numbness, hearing

problems, emotional instability, loss of ability to concentrate, loss of abstract thinking, and loss of judgement (Alves, Colohan, O'Leary, Rimel, & Jane, 1986; Baggerly, 1986; Coonley-Hoganson, Sachs, Desai, & Whitman, 1984; Dikmen, McLean, & Temkin, 1986; Fisher, 1985; Stevens, 1984).

Many post traumatic brain injury symptoms may not become evident until patients have left the health care facility and are home with their family. These symptoms can lead to frustration, anger, and depression on the part of the caregiver, and can have dramatic ramifications for the family as they readjust after the brain injury (Livingston, Brooks, & Bond, 1985 A; Mauss-Clum, & Ryan, 1981; Sanguinetti & Catanzaro, 1987). Individuals with a brain injury are dependent on their family for physical and emotional support. In order to provide this support, family caregivers must be prepared. Nursing can prepare families by providing emotional support and addressing the families' educational needs concerning the injury (Berrol, 1989).

The family may be unable to anticipate post traumatic symptoms because of their concern for the patient's condition while in the acute care setting. They frequently seek information about their loved one's potential outcome, but they also need assistance in caring for that loved one. Nurses in the acute care setting incorporate patient and family teaching into their care planning. However, they

often don't anticipate problems the family may encounter once the patient is discharged. Throughout hospitalization the nurse in the acute care setting has developed rapport with the family and is in the ideal position to inform the family caregiver of the potential for post traumatic symptoms, including cognitive dysfunction and behavioral changes in the patient after discharge (Sanguinetti & Catanzaro, 1987). Providing discharge instructions on post traumatic symptoms may prepare the family for caring for their loved one at home. It may also lessen the emotional stress associated with these symptoms.

The purpose of this study was to determine if the addition of information on cognitive dysfunction and behavioral changes as part of discharge instructions would increase the ability of family caregivers to select appropriate caregiver actions related to specific post traumatic brain injury symptoms.

CHAPTER TWO

Literature and Conceptual Framework

Discharge instructions for family caregivers of brain injured individuals must provide caregivers with information on post traumatic brain injury symptoms, so that they may select appropriate actions related to those symptoms. To develop these instructions nurses must understand post traumatic brain injury symptoms, which include physical and cognitive dysfunction, and behavioral changes. One must also ascertain what stressors the family feels related to the brain injury, and what information would be helpful to the family as they care for their loved one. Literature was reviewed in the areas of cognitive dysfunction, stress experienced by family members of brain injury patients, and family education.

Cognitive Dysfunction

It has been well documented that cognitive dysfunction is a sequelae of minor, moderate, and severe traumatic brain injury (Alves et al., 1986; Fisher, 1985; Grinspun, 1987; Rimel, Giordani, Barth, Boll, & Jane, 1981; Rimel et al., 1982; Tabaddor et al., 1984; Warren & Peck, 1984). These classifications (minor, moderate, and severe) are determined by the Glasgow Coma Scale (GCS), which is graded from three to fifteen, the highest number indicating the

least severe brain injury (Jennett & Bond, 1975). Areas of motor response, verbal response, and eye opening are scored numerically. A score of three (the minimum) to eight would indicate a severe traumatic brain injury. A moderate brain injury would be identified by a GCS of nine to twelve and a minor brain injury would receive a score of thirteen to fifteen.

The severity and duration of cognitive dysfunction symptoms are varied related to the location of injury, duration of post traumatic amnesia (PTA), and duration of loss of consciousness. McSherry (1989) felt that the duration of post traumatic amnesia was a better predictor of cognitive impairment than the length of unconsciousness. Stevens (1984) found that those with PTA less than 24 hours had a complete cognitive return, while those with PTA over 24 hours suffered varying amounts of cognitive loss. Jennett's (1981) research however found that even with PTA less than 1 hour, psychological tests that measure information processing showed a high incidence of abnormality within one day of injury. McSherry (1989) reported that individuals with a mild brain injury were slower on multiple choice reaction time tests than a matched control group. The tests required increased attention and information processing skills (McSherry). Although there was lack of agreement on classifying brain injuries, all seem to agree that there were physical and cognitive sequelae of varying proportions after brain injuries.

Post traumatic brain injury symptoms include somatic, psychophysiologic, and psychosocial parameters, manifested as headache, dizziness, memory problems, numbness, hearing problems, emotional instability, loss of ability to concentrate, loss of abstract thinking, and loss of judgement (Alves et al., 1986; Baggerly, 1986; Coonley-Hoganson et al., 1984; Dikmen et al., 1986; Fisher, 1985; Rimel et al., 1982; Sanguinetti, 1986; Stevens, 1984; Tabaddor et al., 1984). These problems may become apparent within 24 hours of injury or not surface until the individual is home in familiar surroundings. Unless persons have a physical disability as a result of the brain injury, they often appear to be completely normal.

Rimel et al., (1982) evaluated 170 patients at three months post injury. Their convenience sample consisted of persons who had experienced a moderate brain injury. In this descriptive study, 90 percent of the population had memory difficulty and 93 percent complained of headache three months post injury. These were subjective complaints voiced on an assessment by a neurosurgeon and nurse. A small subset (n = 32) of this group was given neuropsychological testing and showed deficits in neurological functioning. These deficits were evident in the areas of new problem-solving skills, memory, concentration, and focusing attention. In reviewing this study, it was criticized that the sample included persons with a history of previous brain injury, as well as those

who may have had neuropsychiatric disorders or alcohol and drug abuse. It is unknown how those factors may have affected their ability on neuropsychological testing.

In a smaller (n = 19) nonrandomized study, Dikmen et al. (1986) compared individuals with a minor brain injury (GCS = 12-15) to noninjured individuals on several neuropsychological tests and psychosocial measures. There was a significant ($p < 0.05$) difference in the injured group on 2 of the total 21 neuropsychological measures at one month after injury. The two differences noted were on 1) tests requiring concentration and 2) newly learned information (Dikmen et al.). The Sickness Impact Profile was used to measure the individual's perception of how the brain injury impacted their daily lifestyle (Dikmen et al.). This profile measures changes in activities of daily living such as sleeping, emotional behavior, and social interactions as they are related to one's state of health (Dikmen et al.). There was a significant amount of dysfunction after one month on physical measures such as daily hygiene, as well as higher functions, such as emotional behavior and social interactions (Dikmen et al.). No significant differences were found in the groups at one year post injury on either measure. Patients with preexisting conditions were excluded from this study.

Although Rimel et al. (1982) and Dikmen et al. used the same neurological battery of tests, the results were inconsistent. Rimel et al. indicated more severe deficits

in their study than did Dikmen et al., which may be attributed to including those with prior brain trauma in the Rimel et al. study or only giving the neuropsychological testing to selected individuals. By only testing a small group, individuals with more severe deficits may have fallen into this group, as there was no indication that it was randomized assignment. Dikmen et al. used a control group of non injured individuals to compare findings while Rimel et al. compared their subjects to normative data. Group norms may differ on factors such as preexisting conditions, age, and education from the actual control group. Both of these studies supported symptoms of cognitive dysfunction after a minor brain injury.

In a similar study, Tabaddor et al. (1984) evaluated 68 patients with moderate and severe brain injuries at three, six, and twelve months after injury. Subjects in this study were evaluated using only a battery of neuropsychological tests, unlike the Rimel et al. study in which clients received a physical assessment as well. These tests measured intellect, language, fine motor coordination and memory. Scores varied from borderline to defective and were consistently below the normative mean in all areas tested (Tabaddor et al.). Consistent with the Dikmen et al. (1986) study, improvement was noted over a one year period in all areas except memory. This study did not compare a noninjured group, but like the Rimel et al. (1982) study, subjects were compared to normative data.

Through phone interviews, 262 patients with mild brain injuries were surveyed for post concussion syndrome (Coonley-Hoganson et al, 1984). Post concussion syndrome is an ill defined term to indicate physical and cognitive dysfunction after a mild brain injury. Of those surveyed, 65 percent reported symptoms at 48 hours post injury and 40 percent reported deficits at one week. The most frequently occurring complaints after 48 hours were headache (52%), dizziness (14%), drowsiness (14%) and nausea or vomiting (12%). Although these were the most frequent complaints at 48 hours, after one week all complaints had decreased considerably. Through interviews, 3.9 percent reported behavior changes and 1.3 percent indicated memory problems after one week. This study seems to support more physical complaints as post concussion syndrome rather than cognitive dysfunction. This study did not assess individuals past one week so it is unknown how many sequelae would still be present at one month to compare to the Dikmen et al. (1986) and Rimel et al. (1982) studies.

Rusonis (1990), in a review of multiple studies, described cognitive dysfunction in adolescents after traumatic brain injury. These studies included individuals with minor to severe brain injuries. Dysfunctions included intellectual functioning, memory impairment, and abstract thinking. Several studies reviewed by Rusonis indicated that student's intelligence quotient (I.Q.) decreased after a brain injury, but showed improvement over 5 years. Of

those persons who recovered motor function and I.Q., many still had memory impairment. There was also much difficulty grasping complex ideas, isolating details and transferring knowledge into action. It was noted that adults, who have had a brain injury, return to a job that they know very well, whereas adolescents return to school where they are expected to learn new information. This would present different problems to the student, as often it is learning new information that is the most difficult. This corroborates the findings of Dikmen et al. (1986).

Although each of these studies examined different populations of persons with minor to severe brain injuries, all identified some post traumatic symptoms of varied duration and severity. The highest percentage of these problems presented immediately after the brain insult, while some symptoms, especially memory deficits, persisted for a year. Some physical complaints were experienced, but the vast majority identified symptoms of cognitive dysfunction after a brain injury. Most of these studies described the signs and symptoms of brain injury. The studies only alluded to family stress related to injury, and offered little information on coping with these symptoms.

Family Stress Related to Injury

Families of traumatic brain injured persons initially are in a crisis state and express shock and denial (Rogers & Kreutzer, 1984). The unexpectedness of the situation adds to their feeling of helplessness. In the acute stage their

only concern may be for their loved one's survival. As their family member's condition stabilizes, they may become overly optimistic about the outcome. Often it is not until the person is discharged, and the family is without professional resources, that they realize some of the problems they will face (Sanguinetti, 1986).

Family members described changes in their loved one after a brain injury that included, decreased memory, dependency, depression, impatience, decreased ambition, and temper outbursts (Mauss-Clum, & Ryan, 1981). Behavioral problems were the most frequently reported source of family stress. These behavioral problems made the families recognize that the brain injury was still causing problems (Fisher, 1985). It may be that family stress was induced because behavioral problems were not as visible as physical disabilities or that the family members were not informed of potential behavioral problems. Although the individual may have physical disabilities, it was cognitive dysfunction with associated behavioral changes that was most stressful for the family to understand and accept (Grinspun, 1987).

McKinlay, Brooks, Bond, Mertinage, and Marshall (1981) interviewed 55 family members of persons with severe blunt brain injury. Family members were interviewed at three, six, and twelve month intervals to determine if psychosocial behavior in the patient changed over a period of time. Subjects were asked to report, through a structured interview, any changes in their family member since the

injury. They also rated their level of stress, as a result of these changes. Symptoms of mental changes were more frequent than physical symptoms. The mean level of stress for family members remained consistent at 3.5 (on a scale of 1 being no stress to 7, severe stress) over the one year time period and was not simply a reflection of the severity of injury. Grinspun (1987) also indicated that the family stress level had no direct relationship to the severity of the initial brain injury.

Two studies were undertaken to evaluate the impact of severe brain injury on the psychosocial functioning of relatives (Livingston, Brooks, & Bond, 1985 A; Livingston, Brooks, & Bond, 1985 B). Three months after injury, Livingston et al. (1985 B) evaluated a convenience sample of 42 relatives of brain injured individuals. They attempted to determine 1) if relatives suffered significant psychiatric disturbances, 2) if social functioning was related to the severity of injury, and 3) which relationship, marital or parental, was more vulnerable. The relatives of brain injured persons showed significant psychiatric disturbances when compared to a control group. These disturbances were most significant in anxiety and insomnia ($p < 0.001$), and social dysfunction ($p < 0.01$). There was a significant disturbance in marital functioning with wives of the brain injured exhibiting more anxiety than those in the control group ($t = 1.77$ $p < 0.04$, $t = 2.14$ $p < 0.01$). In another study (Livingston et al., 1985 A) the

same sample was evaluated at three, six, and twelve months to determine if psychiatric and social functioning of relatives altered throughout the year. Their findings indicated that there were no statistically significant differences in the psychiatric functioning of relatives throughout the year. Scores were statistically significant ($t = 2.21$, $p < 0.03$) in the area of social adjustment at three to six months but not six to twelve months ($t = 0.10$, $p < 0.92$). The level of subjective complaints by the brain injured individual was the most frequent predictor of the psychiatric and social functioning of relatives.

Consistent with McKinley et al. (1981), Stavros (1987) found that the major impact on families was related to psychological and emotional changes in their loved one. As a result of these problems, family caregivers have felt frustration, anger, and guilt, adding to the stress level of the family as they attempted to rebuild their life after traumatic brain injury. Other symptoms exhibited by the patient that increased family stress were impaired social perceptiveness, self regulation, and emotional alterations such as silliness, lability and irritability (Rao, Sulton, Young, & Harvey, 1986).

Family members have reported that behavioral changes involving emotions and cognitive dysfunctions, especially poor memory, were the most frequent problems associated with their family member with a brain injury. Personality changes and the memory deficits were more stressful than the

physical disabilities. Although there was well documented evidence, in the preceding literature, of family stress related to a family member with a brain injury, there was little information on measures to cope with the situation.

Family Education

After reviewing the literature on cognitive dysfunction and family stress related to brain injury, it was apparent that family education is needed to assist families in caring for their loved ones. Providing patient and family education related to a disease process is part of nursing. The nurse in the acute care setting assesses a patient as part of a family and community system, and develops a plan of care. This plan of care should include discharge instructions to meet the client and family needs, once they are home. Family caregivers of brain injured individuals have stated that they were not aware that cognitive function returns more slowly than physical function after a brain injury, and they requested information on this process (Grinspun, 1987). Many have expressed the need for information on the patient's potential outcome, problems, and constructive ways of intervention (Marshall et al., 1988).

Written discharge instructions were provided for 262 patients with a mild brain injury who were treated and released from the emergency department (Coonley-Hoganson et al., 1984). In follow up interviews at forty eight hours and one week after the injury, 84 percent stated that the

instruction sheet answered their questions, and 86 percent said that they understood the instructions (Coonley et al.) The instruction sheet was helpful but further information was needed as 24 percent (n = 62) of the patients found it necessary to contact their physician during the week post injury.

Kozak and Yura (1989) compared teaching methods of emergency department discharge instructions after brain injury. The purpose of their study was to determine if there was a significant difference in recall and understanding among persons receiving one of three discharge teaching methods. The three methods included: 1) preprinted instruction sheet only, 2) instruction sheet and verbal instructions by a nurse, and 3) instruction sheet, verbal instructions, and reinforcement. A total of eighty subjects received discharge instructions during the study period, and thirty three agreed to participate in the study when called back 48 hours later. Although group three had the highest mean score (13.4 out of 19) on an evaluation questionnaire, it was not significantly different than those who received only the instruction sheet and verbal instructions from a nurse (mean = 12.9). There was no significant difference among the groups regarding compliance. In this particular study reinforcement by a nurse did not seem to make a statistical difference. It was discovered that the instructions sheets were written at a ninth grade reading level which presented a limiting factor. Instruction sheets

should have been written at a fifth grade level for more complete understanding of a larger range of individuals (Kozak & Yura). Providing discharge instructions by videotape may decrease this limitation by adding visual as well as verbal communication. Words used should be easily understood by anyone not familiar with technical medical terms.

Family education is also important for those whose family member experienced a cerebral vascular accident or cranial surgical intervention, as they may have physical or cognitive dysfunction (Pasquarello, 1990; Hannegan, 1989; Sanguinetti, 1986). Pasquarello evaluated patient outcomes after the implementation of a nurse managed acute stroke program, which included family education. It was found that the length of stay and recidivism declined and compliance with medication and followup improved (Pasquarello). Although the findings were positive, family education was only one component of the program, and it is unknown to what extent this affected the findings. Jones (1981) also supported family education. In her study describing outcomes following closed brain injury, she indicated that those with mild brain injury respond best to intensive personal interaction, which can be accomplished most cost effectively in the home setting with a well prepared family.

Hannegan (1989) described changes in behavior, attention, intellectual ability, and personality that occur after craniotomy. These changes seem to diminish six weeks

to six months after surgery. It was suggested that complete neuropsychological testing be completed prior to an elective craniotomy to provide a baseline and then repeated after surgery. A thorough family assessment to determine the patient's support system following discharge was also suggested. Because the cognitive and behavioral deficits are a major source of stress to the family, the neuroscience nurse must take an active role in educating the family about these deficits (Hannegan). Structuring the environment, reality orientation, and a daily routine were suggestions provided to assist families in coping with a brain injured person (Hannegan).

Sanguinetti (1986) provided discharge instructions to 29 family caregivers of brain injured individuals. These brain injuries were a result of trauma, cerebrovascular accidents, and postsurgical interventions. Cognitive dysfunction was found to be a sequelae of these conditions. Patients with trauma induced brain injuries experienced cognitive dysfunction of memory, information processing, problem solving, and stimulus discrimination (Sanguinetti). The dysfunction was related to specific physiologic damage as a result of trauma (Sanguinetti). Cognitive dysfunction from surgical interventions or cerebrovascular accidents were the result of a specific focal lesion. These deficits included speech problems, visual processing, and language. In reviewing the literature, Sanguinetti found a high incidence of family stress related to cognitive dysfunction

in their loved ones. Her study attempted to answer the question of whether family caregivers could identify cognitive dysfunction, after viewing videotaped discharge instructions, and apply that information to written simulated situations (1987).

The subjects in the Sanguinetti (1986) study were a convenience sample of family caregivers of individuals, age 16 to 66, that were admitted to an intermediate neurosurgical unit. Subjects were spouses, partners, or parents of the brain injured individuals, who would function as primary caregivers upon discharge (Sanguinetti). Only one family member was selected to participate in the study. The subjects were divided into a control group, which observed a videotape on the physical sequelae of a brain injury and an experimental group, which received information on physical and cognitive dysfunction after brain injury. Two videotapes were developed by the investigator to provide information on physical symptoms after brain injury and cognitive dysfunction after brain injury. A pilot study was undertaken to determine the number of subjects needed to establish statistical significance between the experimental and control groups, subject comprehension of the test, and internal consistency of the instrument (Sanguinetti). Some changes were made in the instrument due to the difficulty in comprehension of the questions.

Sanguinetti's (1986) results showed a statistically significant difference ($t = 10.93$, $p < 0.001$, $df = 27$) in

the mean scores of the two groups on the post test analysis. This supported the hypothesis that there was a difference in the caregivers' ability to extrapolate information on cognitive dysfunction and apply it to written patient care scenarios in the group that received the cognitive dysfunction information compared to the group who did not.

Because of the small sample size Sanguinetti's (1986) study was not generalizable to another population. Her subjects consisted of family members of individuals with a neurological insult of some type. There was no indication of the patient's level of Glasgow Coma Scale, or if these individuals went to rehabilitation before going home. Only one subject per family, including spouses, parents, or partners were considered in the sample. She gave no specific reason for this decision. It would seem that having more than one subject from a family would not only increase the sample size sooner, but also enhance the family education about cognitive dysfunction post brain injury. Adult children, over the age of 18, may be the primary caregiver for a parent and therefore would benefit from the information. Demographic factors were obtained about caregivers and patients to determine the similarities of the groups. Her results indicated that mean post test scores of the two groups were not explained by demographic factors. It was difficult to understand how the age, sex, or education level of the patient might have an effect on a caregiver's response on a post test. Although she described

cognitive dysfunction in her research, she also included behavioral changes in her videotaped instructions. Cognitive dysfunction and behavioral changes were reflected in post traumatic brain injury symptoms. Two versions of the cognitive dysfunction discharge instructions were used to control for the extraneous variable of tape order. There was no statistically significant difference in the post test scores related to the version of the videotape.

Random assignment was accomplished by using a random number table. This led to an unequal number of subjects in the two groups. It was suggested that when the study is replicated only the first subject be randomly assigned and all subsequent subjects alternate between groups. This would result in more equal representation in the groups.

Conceptual Framework

Neuman's System Model (Neuman, 1989) is an appropriate conceptual framework to use when developing an educational plan for family members of brain injured individuals. Neuman defines the client, the family caregiver, as a system composed of physiological, psychosocial, developmental, sociocultural, and spiritual variables. Each individual is composed of a central core, which is their basic structure. Surrounding the central core are the lines of resistance, which help the person defend against stressors. The normal line of defense is the individual's usual state of wellness. The flexible line of defense is the outward most protective buffer which the person has developed over time (Figure 1).

Graphic Representation of the Client System,
Neuman's System Model

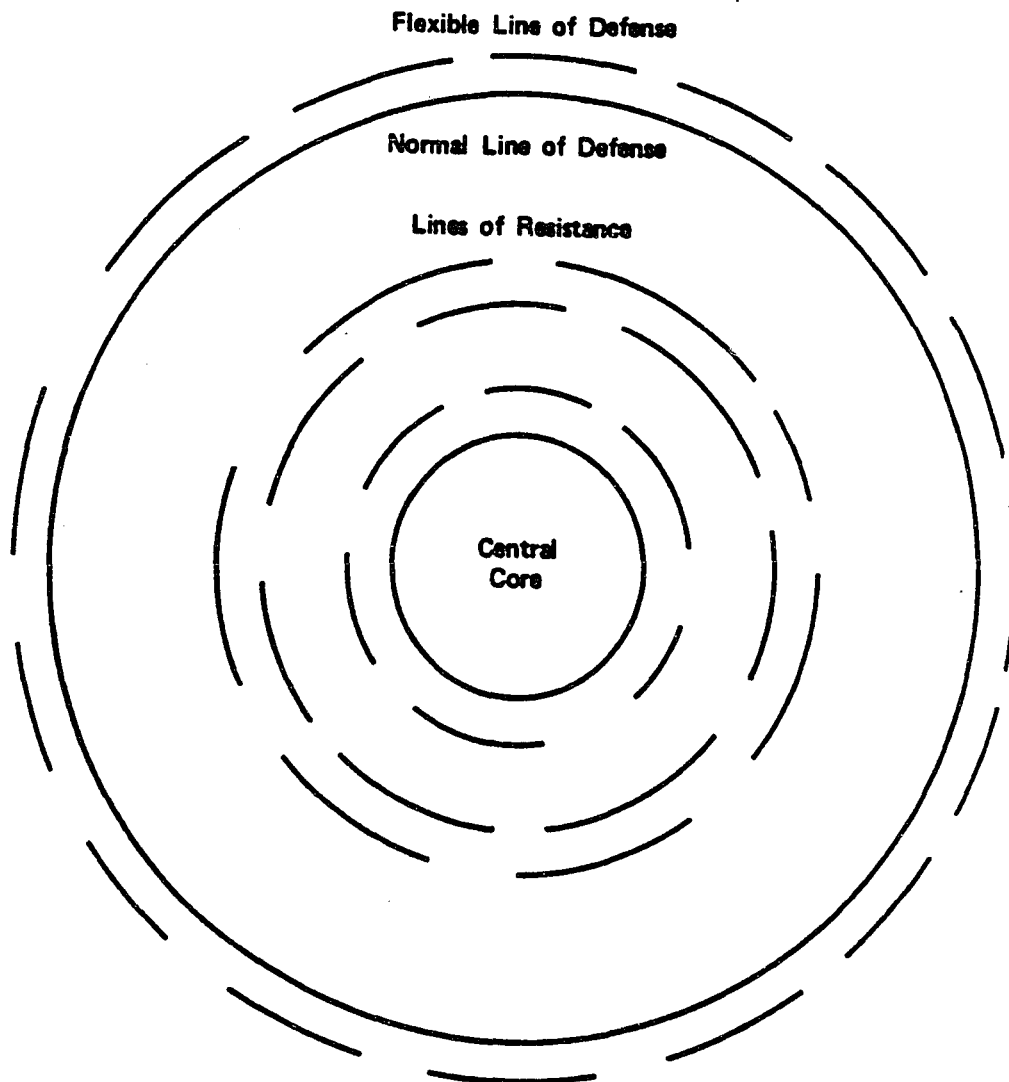


Figure 1. A graphic representation of the client system from Neuman's System Model. Used with permission: Fawcett, J. (1989). Analysis and Evaluation of Conceptual Models of Nursing (2nd ed.). Philadelphia: F. A. Davis Company.

Stressors may cause the individual to respond or react. Stressors are classified as being within the person, in the external environment, or in the distant external environment. The goal of nursing is to assist the client to maintain their wellness state through identification of stressors and adaptation or elimination of them. This is accomplished through primary, secondary, or tertiary prevention (Neuman). Primary prevention occurs before the individual is impacted by the stressor. Secondary prevention is used to strengthen the internal lines of resistance once symptoms have occurred. Tertiary prevention is used to maintain the optimal wellness level once secondary preventions have occurred (Figure 2).

The family members of an individual with a moderate brain injury, as described by a Glasgow Coma Scale of 9-14 at six hours after hospital admission, often express signs of stress related to the personality changes of their loved one. According to Neuman's System Model (1989) these family members have had their flexible line of defense and their normal line of defense penetrated by the stressor of their loved one's brain injury (Figure 3). The flexible line of defense is the family's protective buffer which assists them in preventing stressors from breaking through the normal line of defense (Mischke-Berkey, Warner, & Hanson, 1989). The normal line of the defense for the family is their adaptation over time and how they cope as a family to problems or crises (Mischke-Berkey et al.). The goal of

The Neuman's System Model

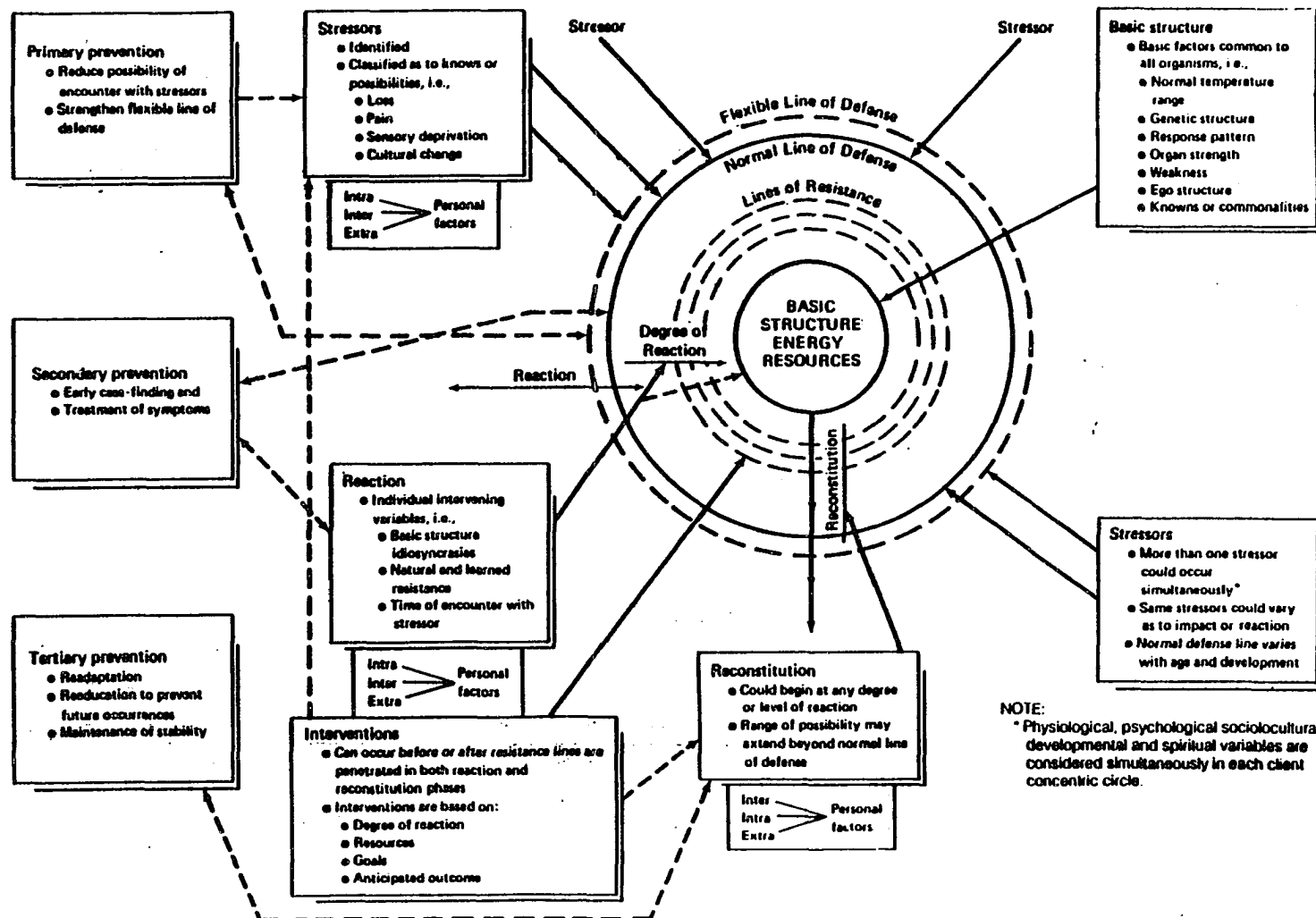
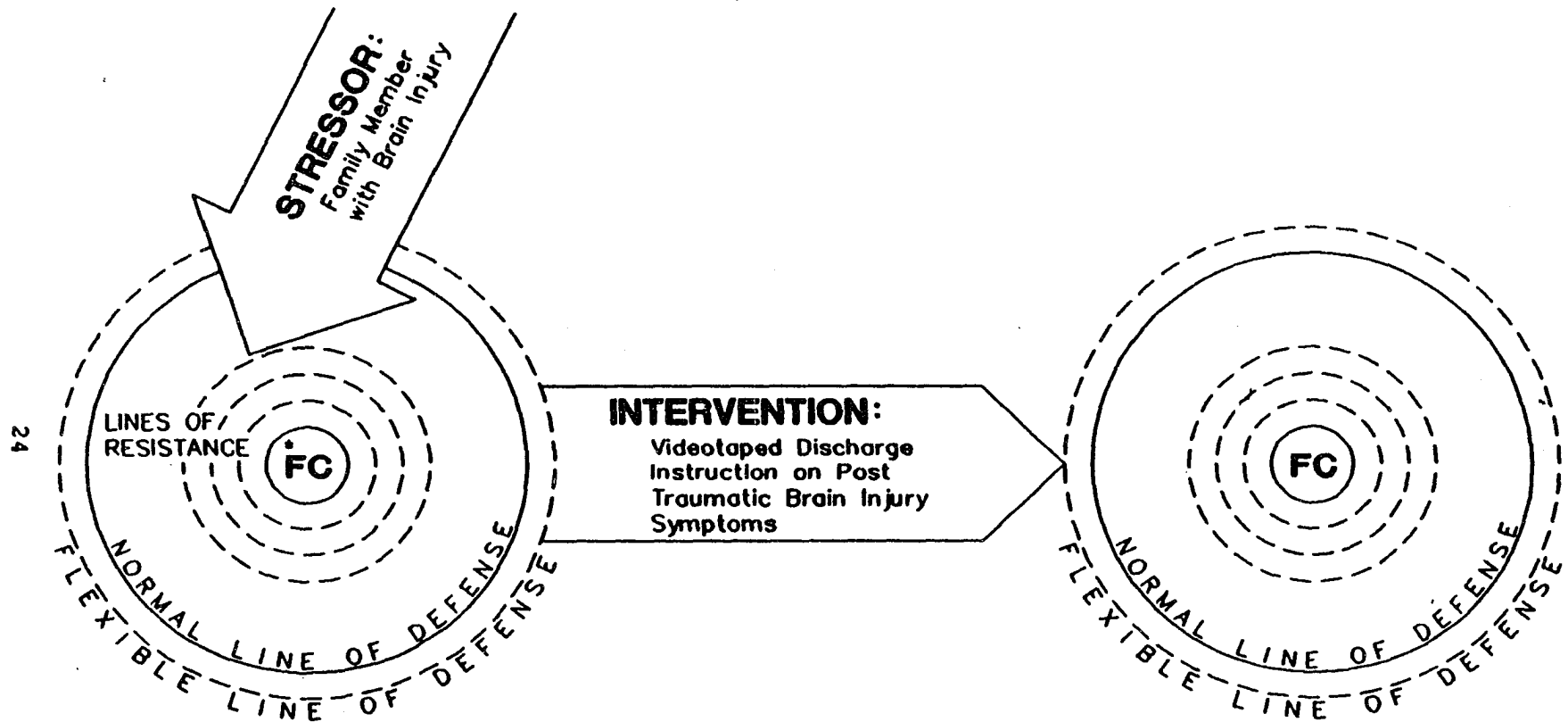


Figure 2. The complete diagram of the Neuman Systems Model developed by Betty Neuman. Used with permission: Neuman, B. (1989). The Neuman Systems Model (2nd ed.). Norwalk, CT: Appleton & Lange.

Stressor Impact on Family Caregivers



* F.C. Family Caregiver
Brings to situation past experience.
Motivated to learn due to lack of
information on brain injury.

Family Caregiver after intervention.
Flexible line of defense and normal
line of defense restructured.
Measured through post test analysis.

Figure 3. This diagram identifies the stressor impact of a family member with a brain injury on the family caregiver. The intervention, videotaped discharge instructions on post traumatic brain injury symptoms is instrumental in restructuring the flexible line of defense and the normal line of defense.

nursing is to assist the client (the family caregiver in this case) in returning to their optimal state of wellness by reducing the stressors affecting them (Neuman). Nursing interventions are actions to support the family in responding to an actual stressor, that of a loved one with a brain injury, and help them generate health promoting behavior for the family unit. This will be accomplished by providing discharge instructions on post traumatic brain injury symptoms. Discharge instructions would be considered primary prevention. The family caregiver may not be experiencing stress related to the family member's brain injury while the person is still hospitalized, therefore the discharge instructions would be primary prevention.

In developing discharge instructions for family caregivers, one must consider that as adult learners, family members are stimulated to learn because they sense a gap in their information about a subject (Knowles, 1984). Family caregivers may be motivated to learn about post traumatic brain injury symptoms in order to understand the changes in their loved one. Potential complications and the family's prior knowledge of brain injury are critical learning needs of the family as they prepare for discharge (Rankin, 1990). Also to be taken into consideration are what skills and equipment the family may need at home to manage the problem (Rankin). Adult learning is personal and private, and new ideas must relate to old information (Even, 1987). Family learning also occurs through concrete knowledge provided in

a manner in which knowledge interacts with experience (Even). By providing discharge instructions on videotape describing not only post traumatic brain injury symptoms, but also actions to be taken, family caregivers can associate the knowledge to action. Learning will be facilitated because the new information will assist in problem solving as they care for their loved one. Included in the goals for family education are the continuity of the rehabilitation process, keeping the client safe, and assisting the family in the coping process (Grinspun, 1987). This will be accomplished by providing information and methods for resolution of situations that may be encountered at home.

Summary

In reviewing the literature, it was apparent that there were large numbers of individuals who suffered the effects of post traumatic brain injury symptoms. These symptoms were of a cognitive, physical, or behavioral nature, and varied depending on the length of unconsciousness, and post traumatic amnesia. Family members repeatedly indicated that behavioral and personality changes, and difficulties with social situations were more troublesome than the physical disabilities of their loved ones. Because their flexible line of defense had been penetrated they needed nursing resources to assist them to rebuild this line of defense. These same family members were expressing a desire for information on post traumatic brain injury symptoms and

therefore demonstrating their willingness to learn about the subject. Nurses are in the ideal situation to provide this education which will hopefully assist the family to continue the rehabilitation process at home, and also support the family as they cope with the individual changes post brain injury.

Research Question

Does the addition of information on cognitive dysfunction and behavioral changes as a part of discharge instructions increase the ability of family caregivers to select appropriate caregiver actions for specific post traumatic brain injury symptoms?

Research Hypothesis

There will be a significant increase ($p = .05$ level) in family caregivers' ability to select appropriate caregiver actions for post traumatic brain injury symptoms by caregivers who receive information on cognitive dysfunction and behavioral changes when compared to caregivers who do not receive this information.

Definition of Terms

Discharge instructions are videotaped information on physical symptoms (Appendix D), cognitive dysfunction, and behavioral changes after a brain injury (Appendix E). These instructions will be provided to family caregivers prior to the patient being discharged home.

Physical dysfunction refers to changes of a physical nature that may occur as a result of a brain injury. They

include: 1) unequal pupils, 2) blurred or double vision, 3) confusion, 4) disorientation, 5) drowsiness or impairment of consciousness, 6) headache, 7) vomiting, 8) irritability, 9) muscular weakness, 10) neck pain, 11) poor coordination, 12) stiff neck, and 13) seizures.

Post traumatic brain injury symptoms refers to those symptoms of a physical or cognitive nature in addition to behavioral changes related to the brain injury. Cognitive dysfunctions include: 1) short term memory deficits, 2) decreased learning ability, 3) diminished ability to think abstractly, 4) decreased ability to concentrate, 5) inappropriate word usage, and 6) difficulty with multiple stimuli. Behavioral changes include 1) lack of initiative and motivation, 2) changes in mood, 3) increased susceptibility to fatigue and 4) lack of awareness of condition.

Family caregivers are family members including spouse, partner, parents, children, or other relatives who will provide direct care and support in the home setting.

CHAPTER THREE

Methodology

Design

A post test only experimental design was used to test the hypothesis that there would be a significant increase in family caregivers' ability to select appropriate caregiver actions for post traumatic brain injury symptoms by caregivers who received information on cognitive dysfunction and behavioral changes when compared to caregivers who did not receive this information. The independent variable was discharge instructions. The dependent variable was the caregivers' scores on a post test. Subjects were randomly assigned to one of two groups. The control group received videotaped discharge instructions on physical symptoms after a brain injury (Appendix D). The experimental group received videotaped discharge instructions on physical symptoms, cognitive dysfunction, and behavioral changes after a brain injury (Appendix E). After viewing the videotapes, subjects in both groups took a post test consisting of six questions related to the content of the discharge instructions regarding post traumatic brain injury symptoms and appropriate caregiver actions.

Sample

Subjects for this study were chosen from family caregivers of patients with a mild or moderate brain injury. This was defined by a Glasgow Coma Scale (GCS) of 9-14, six hours after admission, any period of loss of consciousness (LOC), or post traumatic amnesia (PTA). This group was chosen because patients with a mild to moderate brain injury have a high likelihood of having post traumatic brain injury symptoms including physical, cognitive, and behavioral changes. They were also more likely to be discharged home. Those with severe brain injury (GCS 3-8) were more likely to remain comatose longer and be transferred to an inpatient rehabilitation setting before being discharged home, therefore the family members of those patients were excluded from the study. Family members of patients who had a GCS 9-14 and were discharged to a rehabilitation facility were included.

A convenience sample was obtained from family caregivers of brain injured individuals, as they were admitted to the institution. Random assignment was accomplished by a flip of the coin. The first family subject was assigned to the control group, the second family subject to the experimental group, and all following family subjects were assigned to alternate groups.

Patients who met any of the criteria (GCS, LOC, or PTA) were identified by the nurse researcher within 24 hours of admission. This was accomplished by reviewing the records

of all trauma patients admitted since the last day the researcher worked. Once patients were identified, who met the criteria, it was determined if they had family caregivers. Spouses, partners, parents, children, or other relatives, over the age of eighteen, who would serve as caregiver upon discharge, were identified. The subjects were caregivers of patients over the age of 14, as pediatric patients may experience age related post traumatic brain injury symptoms which were not addressed in the discharge instructions.

Demographic data were obtained on all subjects to describe the sample. Twenty subjects were female (67%) and ten subjects (33%) were male. Caregivers consisted of wives (4), mothers (4), fathers (2), sisters (4), brothers (2), sons (5), daughters (5), girlfriends (3), and one husband. Sons and daughters comprised 34 percent of the total. Ages of caregivers ranged from 18 to 72 with 27 percent (8) being between the ages of 36-45. The majority of caregivers (67%, n = 20) had only a high school education. When asked about previous experience with someone with a brain injury, 80 percent (24) had no previous experience. Ninety percent (27) had no previous involvement with a brain injury support group or rehabilitation center (Table 1).

Table 1

Summary of Demographic Results

	Group			
	Control		Experimental	
	N	(%)	N	(%)
Caregiver Age				
18-27	1	(9%)	3	(16%)
27-36	0	(0%)	5	(26%)
36-45	5	(45%)	3	(16%)
45-54	2	(18%)	1	(5%)
54-63	1	(9%)	3	(16%)
63-72	2	(18%)	4	(21%)
Caregiver Sex				
Male	3	(27%)	7	(37%)
Female	8	(73%)	12	(63%)
Highest Level of Education				
High School	7	(64%)	13	(68%)
Associate Degree	0	(0%)	4	(21%)
Bachelor Degree	2	(18%)	2	(11%)
Masters Degree	0	(0%)	0	(0%)
Other	2	(18%)	0	(0%)
Relation of Caregiver to Patient				
wife	3	(27%)	1	(5%)
mother	1	(9%)	3	(16%)
father	1	(9%)	1	(5%)
sister	2	(18%)	0	(0%)
sister in law	0	(0%)	2	(11%)
son	2	(18%)	3	(16%)
daughter	1	(9%)	3	(16%)
girlfriend	0	(0%)	3	(16%)
brother	0	(0%)	2	(11%)
husband	0	(0%)	1	(5%)
granddaughter	1	(9%)	0	(0%)
Previous experience with brain injury				
Yes	2	(18%)	4	(21%)
No	9	(82%)	15	(79%)
Previous Rehab involvement				
Yes	1	(9%)	2	(11%)
no	10	(91%)	17	(89%)

Instruments

The control group viewed a 13 minute videotape that reviewed physical symptoms after a brain injury that their loved one might experience, as well as instructions on what to do about the problems. The experimental group viewed a 19 minute videotape with instructions on post traumatic brain injury symptoms including physical, cognitive dysfunction, and behavioral changes. This tape provided information on actions to be taken should the problems related to the post traumatic brain injury symptoms occur. This videotape was developed by Mary Sanguinetti (1986) for use in her research on discharge instructions. Permission was received to use her tool in this study (Appendix G). Information on cognitive dysfunction and behavioral changes, provided on the videotape, was gathered from a review of the literature.

Both groups received a post test consisting of six scenarios depicting circumstances typical of daily life events (Appendix A). Each description highlighted one cognitive dysfunction or behavioral change as it might disrupt daily living. Caregivers were asked to read the scenario, name the problem the patient was experiencing, and what action the caregiver could take to resolve the problem. Scoring of the post test consisted of five groupings: 1) correct answer with the correct reason, 2) correct answer with the incorrect reason, 3) incorrect answer with the correct reason, 4) incorrect answer with incorrect reason,

and 5) no response. The overall score was calculated using the following formula: zero points for an incorrect answer and incorrect reason, one point for an incorrect answer with a correct reason, one point for a correct answer with an incorrect reason, and three points for a correct answer with a correct reason. Those who gave no response were given zero for that question. As there were six scenarios, there was a possibility of a minimum score of zero and a maximum score of 18.

This instrument was developed by Mary Sanquinetti (1986) and internal reliability was established using linear regression and comparing total scores for odd-numbered questions to even numbered questions. This resulted in a Pearson's r value of .84 on the post test. The Spearman-Brown prophecy formula was used to give an estimated reliability coefficient of .92. A coefficient alpha analysis was performed which resulted in reliability coefficient of .90. Face and content validity were established for the scenarios in the posttest through evaluation by a professional neuroscience nurse, a nurse educator, a neuropsychologist, a neuroscience clinician, and a staff nurse on a neuroscience unit.

Procedure

Within twenty four hours of admission (or Monday morning after a weekend) a family member, of patients who met the criteria, were approached by the researcher. The researcher introduced herself as a graduate nursing student

from Grand Valley State University who was evaluating discharge teaching for family caregivers of patients experiencing a brain injury. The family was informed that the purpose of the research was to assess discharge teaching and identify ways to make the primary caregiver more knowledgeable and better prepared to provide care for their loved one at home. They were asked if they would be interested in participating. It was explained to them that they were volunteering and could withdraw at any time. If they wished to participate, they would be asked to sign a consent form. If they did not wish to participate, they were informed that they would receive the standard hospital discharge instructions and would not view the videotapes. Subjects had to be able to read English.

Once subjects were identified as meeting criteria for inclusion in the study the researcher explained the procedure to the subjects and obtain a consent form (Appendix B). At this time the researcher interviewed the family caregivers to obtain demographic data (Appendix C). Once determination was made that the patient was to be discharged home, (this was frequently several days after the initial consent had been given) the researcher provided the appropriate videotape depending on whether the subject was in the control or experimental group.

By a flip of the coin, the caregivers of the first patient admitted during data collection were assigned to the control group. Multiple caregivers within one family were

assigned to the same group. Family subjects were alternately assigned to groups as their loved ones were admitted to the hospital. The control group viewed a 13 minute videotape on physical symptoms after a brain injury (Appendix D). This included signs and symptoms that should be reported to the physician if they occur. They included: unequal pupils, blurred or double vision, confusion, disorientation, drowsiness, headache, vomiting, irritability, muscular weakness, neck pain, poor coordination, stiff neck, and seizures. The experimental group viewed a 19 minute videotape that identified the physical symptoms just described as well as cognitive dysfunction and behavioral changes (Appendix E). Cognitive dysfunction included: 1) short-term memory deficits, 2) decreased learning ability, 3) diminished ability to think abstractly, 4) decreased ability to concentrate, 5) inappropriate word usage, and 6) difficulty with multiple stimuli. Behavioral changes included: 1) self-centeredness, 2) lack of initiative and motivation, 3) changes in mood, and 4) lack of in-depth insight, 5) lack of awareness of condition, and 6) increased susceptibility to fatigue.

After subjects viewed the videotape they were given the post test by the researcher (Appendix A). The post test was immediately corrected by the researcher and the results were discussed with the subject. Explanations of answers and the discharge teaching were provided by the researcher and were individualized for the family caregiver. Members of the

control group, who initially saw the videotape on physical symptoms, viewed the videotape on cognitive dysfunction and behavioral changes after completing the post test. The researcher was the only one to present the videotapes to family caregivers, administer the post tests, score the post tests, discuss results with caregivers, and collect data.

As this study was noninvasive, there was little risk to subjects, however, they may have felt some discomfort or anxiety about the information they received. They were reassured that the purpose was to reduce these feelings of discomfort through education and an understanding of the injury process. At the time caregivers consented to participate, the investigator informed family members that she was available to answer questions Monday-Friday during the day. Subjects may have had a concern about confidentiality. This was addressed by informing subjects that all information was kept confidential and there was no association between the final results of the study and individual responses. There were no names put on the post test or demographic data form. Some individuals may have had a fear of failure on the test. They were reassured by the researcher that there was no pass or fail, and that the purpose of the test was to determine the adequacy of the videotaped instruction.

CHAPTER FOUR

Results

Thirty subjects participated in the study. Subjects included one or more members per family. By a flip of the coin, the first family subject was assigned to the control group. The second family subject was assigned to the experimental group and thereafter each family was assigned alternately to the control or experimental group. There were eleven subjects in the control group and nineteen in the experimental group. Each subject watched one of two versions of videotaped discharge instructions on post traumatic brain injury symptoms. The videotape version seen by the control group consisted of physical symptoms post traumatic brain injury. The experimental group version showed physical, behavioral, and cognitive post traumatic brain injury symptoms. All subjects of one family viewed the same videotape at the same time. A post test was completed by all subjects after viewing the videotape.

There were six questions on the post test with a score of 1-3 points per question for a total maximum score of 18. The scores for the control group ranged from 0 to 7 while the experimental group scores ranged from 0-18 (Table 2).

Table 2

Post Test Scores

Subjects	Group	
	Control	Experimental
1	0	16
2	2	4
3	2	14
4	2	6
5	3	16
6	2	18
7	1	11
8	2	10
9	7	9
10	3	16
11	4	16
12		18
13		14
14		16
15		14
16		12
17		6
18		0
19		5

There were two parts to each question on the post test. Subjects were asked to name the problem the patient was experiencing as the first part of the answer. The second part consisted of identifying what the caregiver would do about the problem. Subjects received one point for a correct answer to either part of the question. If both parts were answered correctly three points were given. Table 3 provides a frequency distribution of correct answers by the question for the control and experimental groups.

Table 3

Frequency Distribution of Correct Answers on Post Test

	Group	
	Control	Experimental
Question 1		
Name the problem	0	10
What would you do	5	18
Question 2		
Name the problem	1	10
What would you do	3	16
Question 3		
Name the problem	2	11
What would you do	1	15
Question 4		
Name the problem	3	10
What would you do	3	16
Question 5		
Name the problem	2	14
What would you do	1	13
Question 6		
Name the problem	6	12
What would you do	0	14

The mean score of the control group was 2.545 and the experimental group mean was 11.632. The standard deviation was 1.809 for the control group and 5.294 for the experimental group (Table 4). A listing of the raw data is presented in Appendix F.

Table 4

Mean and Standard Deviation of Post Test Scores

	Group	
	Control	Experimental
Mean	2.545	11.632
Standard Deviation	1.809	5.294

The means of the two groups were compared, using the unpaired one tail t-test. There was a statistically significant difference between the control and experimental group ($t = 5.475$, $p < .0001$, $df = 28$). The mean score in the experimental group was higher than the mean score of the control group. Those individuals, who indicated previous experience with someone with a brain injury, had a mean score of 2.50 for the control group and a mean score of 13.25 for the experimental group. Subjects in the control group who indicated that they had involvement with a brain injury support group had a mean score of 3.00. In the experimental group, subjects with involvement with a brain injury support group had a mean score of 10.5. Only 3

subjects, all in the experimental group, listed medical occupations and their mean score on the post test was 11.3. One subject in the experimental group and one subject in the control group received a post test score of zero. Therefore, the research hypothesis was supported. There was a significant increase ($p < .0001$ level) in family caregivers' ability to select appropriate caregiver actions for post traumatic brain injury symptoms by caregivers who received information on cognitive dysfunction and behavioral changes when compared to caregivers who did not receive this information.

CHAPTER FIVE

Discussion of Findings

The purpose of this study was to determine if the addition of information on cognitive dysfunction and behavioral changes, as a part of discharge instructions, would increase the ability of family caregivers to select appropriate caregiver actions for specific post traumatic brain injury symptoms. The intent was not just to determine if caregivers could remember what was in the videotaped discharge instructions, but to measure their ability to understand the problem, analyze it and choose appropriate steps to resolve the problem. This was not meant to be the only information to prepare the caregiver to care for their loved one at home, but would be the initial information.

An unpaired t-test was used to compare the means of the control and experimental groups. The mean score from the experimental group was higher than that of the control group. This was statistically significant ($p < .0001$).

Subjects in the experimental group had more correct answers than those in the control group, as evidenced by the higher mean scores. This supported the hypothesis that there would be a significant increase in family caregivers' ability to select appropriate caregiver actions for post traumatic brain injury symptoms by caregivers who received

information on cognitive dysfunction and behavioral changes when compared to caregivers who did not receive this information.

The majority of the incorrect answers given by the experimental group were behavioral or cognitive symptoms, but not the appropriate answer for the description of the problem. Occasionally physical symptoms were given when identifying the problem. Subjects in the experimental group incorrectly identified the problem as confusion or irritability, if they chose an incorrect physical symptom. The symptoms of confusion and irritability were described in the first part of the tape seen by both the experimental and control groups.

Subjects in the control group had fewer correct answers in identifying the problem and determining a solution than the experimental group. Some members of the control group seemed to be able to analyze the scenarios and although they could not identify the problem by the correct name, they seemed to have some understanding about how to resolve the situation. A frequent answer given for identification of the problem was irritability or confusion. These two topics had been discussed in the videotape about physical symptoms, which was shown to the control group. Other subjects answered, "I don't know" when asked to identify the problem.

Many subjects in the control group indicated they would call the physician as a solution regardless of whether they had identified the problem correctly. They would call the

physician in response to behavioral and cognitive dysfunctions. This included such problems as memory loss, labile emotions, and forgetting familiar tasks. It was apparent from that answer that the control subjects were unable to analyze the problem and determine a solution on their own. Very few subjects in the experimental group answered that the caregiver should call the physician as a solution to the problem. Usually this answer was given after suggesting another solution.

Another common theme in the responses of the control group was to rescue the brain injured person. This was indicated by answering that the caregiver would complete the tasks for the patient rather than letting the patient do it independently. Rescuing the brain injured person and calling the physician for behavioral changes and cognitive dysfunction were inappropriate caregiver actions. This indicated that they would not be as prepared to care for their loved one at home and therefore may have increased family stress related to these symptoms.

This study supported the findings of Sanguinetti (1986). Although the findings are similar, her groups were demographically different. Subjects in her study consisted of one spouse, partner, or parent rather than all family caregivers. Subjects were somewhat younger being 16 to 66 compared to this study where they were 18 to 72. It is unknown how this may have affected the study results. The results of her study were statistically significant. The

mean score on the post test was higher for the experimental group than the control group. She did not provide any information on the types of answers that the subjects gave to the questions on the post test.

Adult learners are stimulated to learn when they notice a gap in their learning (Knowles, 1984). New ideas, which are presented to them, must relate to old ideas and interact with their experience (Even, 1987). Some subjects in this study may not have realized that they needed to learn the information provided on the videotapes. If their loved one had not yet exhibited any post traumatic brain injury symptoms, they may have been unable to relate the information presented to their experience. This may have led them to concentrate less on the discharge instructions causing them to retain less information and receive a lower score. Sanguinetti (1986) contacted 20 of her 29 subjects by telephone for a followup interview one to four weeks after discharge. Seventeen individuals (85%) indicated that the discharge instructions had been helpful. The caregivers mentioned memory, word processing, irritability, lability, lethargy, and judgement, as problems that their loved one had exhibited since discharge.

Demographic data were not statistically analyzed, due to sample size, to determine any relationships between occupation, experience with a person with a brain injury, or involvement with a brain injury support group and post test scores. Individuals in the control group who indicated that

they had had previous experience with someone with a brain injury had lower mean scores than the mean for the control group. It was not apparent by their answers that previous experience provided them with information needed to choose correct answers on the post test. The three individuals in the experiemental group, who indicated that they had had previous experience with someone with a brain injury, scored higher than the mean for the experimental group. Perhaps the information on the videotape triggered past learned information or they would have chosen the correct answer without viewing the videotape. Subjects in the control group who indicated that they had involvement with a brain injury support group had a mean score higher than the control group mean score. They may have assimilated some information from the brain injury support group. This did not hold true for the experimental group, as those with previous involvement with a brain injury support group had lower scores than the experimental group mean.

Application to practice

Prior to this study, family caregivers at this institution were provided with verbal instructions only on physical symptoms post traumatic brain injury. It was unknown what other information they may have obtained from other sources to prepare for caring for their loved one at home. Videotaped discharge instructions on post traumatic brain injury symptoms were a convenient method for providing information for family caregivers. Information provided by

this study will be useful to other clinical nurses who may want to replicate the study or develop discharge instructions on their unit.

Discharge instructions on post traumatic brain injury symptoms could be modified to be used in another setting, such as an emergency department. Videotaped instructions could be provided to family caregivers of persons with minor brain injuries, who may be discharged to home from the emergency department. This would enhance the family caregivers ability to understand post traumatic brain injury symptoms and take appropriate caregiver actions. In doing this, return visits to the emergency department, because of cognitive dysfunction and behavioral changes post traumatic brain injury, may be decreased.

Limitations

It was intended that the sample for this study should consist of the caregivers of at least twenty patients in each of the control and experimental groups. Data collection was completed after six months. It was difficult to make contact with the family members, as often they were from out of town. Some only arrived at the hospital to take the patient home. Several family members were approached at that time about participating in the study and consented, watched the videotape and then refused to take the post test. Those family members had arrived at the hospital to take their loved one home and did not have enough time to assimilate the information about the study. This emphasizes

the importance of telling family members about the discharge instructions early in the hospitalization. They may not have seen any of the post traumatic brain injury symptoms in their loved one and therefore not understood the importance of the discharge instructions. Some may just not have wanted to participate for personal reasons. Several family members also expressed that they were very stressed with their loved one in the hospital and had difficulty concentrating on the videotapes.

Although the results of this study were statistically significant, because of the small sample size and single setting, results were not generalizable to other settings. The subjects in this study were family caregivers of patients with traumatic brain injuries. Persons with other brain insults, such as stroke, aneurysm, and craniotomy may also experience some of these symptoms (Hannegan, 1989; Pasquarello, 1990; Sanguinetti, 1986) and their family members could also benefit from the instructions.

Diffusion of treatment was a potential external threat as family caregivers shared a common waiting room. If discharge instructions were provided too long before discharge, families might have discussed and compared the information they had received. Although the intent was to provide discharge instructions within 12 hours prior to the client being discharged, this was not feasible. It was difficult to always know when the client would be discharged. Family schedules often precluded the 12 hour

time frame as well. Discharge instructions were provided whenever it was most convenient for family members. Due to the size of the sample and characteristics of the sample group, the results were not generalizable to another group.

Scoring of the post test was somewhat difficult because the answers were not multiple choice, but were individual responses. The researcher was the only person to score the post tests so there was little chance of multiple interpretation, however the scoring was subject to investigator judgement. This could be addressed by providing multiple choice answers rather than descriptive answers. One would then question if subjects truly understood the material or if they were making a guess when choosing an answer.

Recommendations

Discharge instructions on post traumatic brain injury symptoms should become a routine part of the care plan for family caregivers of those with a brain injury. Included in this group should be caregivers of patients with any brain insult. This would include those with aneurysms, strokes, craniotomies, and traumatic brain injuries. Family members should be made aware of these instructions soon after admission. Family caregivers could view the videotaped instructions at their convenience. They could also view the videotape several times for more complete understanding. To reinforce the information, written discharge instructions should also be provided. The nurse should discuss the

information with family members and answer specific questions that they may have. Although one study (Kozak & Yura, 1989) found that reinforcement by a nurse did not statistically increase compliance or improve scores on a post test, reinforcement may assist family caregivers to comprehend the information better.

A followup phone call, once the patient is home, would also assist family members in caring for their loved one. This could also expand the study. Family caregivers could be called and asked what symptoms their loved one exhibited. Further information could be obtained on the caregiver's ability to resolve the situation and an evaluation made of the discharge instructions. In discussing the situation with the family caregiver once the patient is home, the nurse would be able to address actual patient symptoms with caregiver actions. At that time it may be easier for family caregivers to relate information to experience and they may be more receptive to learning.

To make this more generalizable the study should be conducted in several sites containing a more diverse cultural group. A larger sample size would also add strength to the study.

In addition to better preparing caregivers, it was anticipated that providing discharge instructions on post traumatic brain injury symptoms would decrease stress in family caregivers once they are home. This study did not provide a mechanism to test this aspect and it is

recommended that further research be undertaken. The literature supports that there is family stress related to post traumatic brain injury symptoms (Mauss-Clum & Ryan, 1981; Fisher, 1985; Grinspun, 1987; McKinlay et al., 1981; Livingston et al., 1985 A; Livingston et al., 1985 B; Rao et al., 1986). A natural extension of this study would be to measure family stress levels in two groups. One group would receive the discharge instructions on post traumatic brain injury symptoms and the other group would not. The group who received the discharge instructions on post traumatic brain injury symptoms could also be compared retrospectively to some of the previously studied subjects for stress related to the post traumatic brain injury symptoms.

Summary

This was a small study to evaluate family caregivers' ability to select appropriate caregiver actions following discharge instructions on post traumatic brain injury symptoms. Those who received information on physical symptoms, cognitive dysfunction, and behavioral changes had a higher mean score than those who received only information on physical changes. The hypothesis was supported that there was a significant increase ($p < .0001$) in family caregivers' ability to select appropriate caregiver actions for post traumatic brain injury symptoms by caregivers who received information on cognitive dysfunction and behavioral changes when compared to caregivers who did not receive this information.

Videotaped discharge instructions were a convenient method to provide family caregivers with this information. The primary nurse was able to reinforce the discharge instructions verbally, and provide specific information relative to the caregivers' loved one. In providing these discharge instruction, as primary prevention, it was anticipated that the caregivers flexible line of defense would be strengthened. In this manner they would be able to cope with the changes in their family as a result of the stressor of a family member with a brain injury. This method of discharge instructions is a beginning in preparing the family to care for their loved one at home and possibly lessen the stress associated with caring for a brain injured loved one.

APPENDICES

APPENDIX A

Post Test

Instructions: Read each situation and respond as if you were involved in such a circumstance. Remember, all your information is kept confidential.

1. After the injury, the patient is sitting quietly watching television when suddenly friends drop by and the children come running into the room. You notice the patient beginning to be anxious, appearing confused, and having difficulty focusing on the conversation.

Name the problem the patient is experiencing _____

What would you do about it? _____

2. After the injury, the patient appeared confused when trying to take care of the once familiar tasks of family budgeting and bill paying.

Name the problem the patient is experiencing: _____

What would you do about it? _____

3. Since the injury, the patient has made several appointments for the same time on the same day.
Name the problem the patient is experiencing:

What would you do about it? _____

4. After the injury, the patient remained idle around the house and no longer exhibited interest in favorite hobbies and sports activities.

Name the problem the patient is experiencing: _____

What would you do about it? _____

5. Since the injury, the patient is very demanding of your time, and preoccupied with personal needs.

Name the problem the patient is experiencing: _____

What would you do about it? _____

6. Since the injury, the patient cries easily, is easily agitated, and occasionally exhibits unwarranted anger.

Name the problem the patient is experiencing: _____

What would you do about it? _____

APPENDIX B

Consent Form

I understand that the purpose of this study is to develop appropriate discharge teaching for family members who are going to be caring for patients at home with brain injuries. The benefits of this study will be increased knowledge of the problems the patient may have at home and actions to be taken by the caregiver to deal with the problems.

I also understand that participation will involve 45 minutes of my time. I will view a short videotape on discharge instructions for a person with a brain injury and complete a short questionnaire. It is not anticipated that this study will lead to any physical or emotional risk to myself or my family. The information I provide will be kept strictly confidential and the data will be coded so that I can not be identified.

I acknowledge that:

"I have been given an opportunity to ask questions regarding this research study, and that these questions have been answered to my satisfaction."

"In giving my consent, I understand that my participation in this study is voluntary and that I may withdraw at any time without affecting the care my family member receives from the physician or the staff at Borgess Medical Center."

"The investigator, Connie Pardee, has my permission to show me videotaped discharge instructions about caring for my family member with a brain injury."

"I hereby authorize the investigator to release the information obtained in this study to scientific literature."

"I have been given Connie Pardee's phone number so that I may contact her if I have questions between the hours of 8a.m. and 5 p.m. Monday through Friday ."

"I acknowledge that I have read and understand the above information, and that I agree to participate in this study."

Witness

Date

Participant Signature

Date

APPENDIX C

Demographic Information

Caregiver

Age: _____ Sex M F

What is your highest level of education?

High School Associate Degree Baccalaureate Degree

Masters Degree Doctoral Degree Post Doctoral

Other

Relation of Caregiver to Patient: _____

What is your occupation? _____

Have you had any previous experience with a person with a
brain injury? Y N

Have you had any previous involvement with a Rehabilitation
Facility or Injury Support Group (such as Head Injury
Group)? Y N

Criteria for Caregiver selection

Length of LOC Length of PTA GCS

APPENDIX D

Brain Injury Discharge Instructions

Physical Symptoms (Control Group)

Following a brain injury, there are certain signs and symptoms that should be observed, which may indicate an injury to the Central Nervous System.

The following is a list of these signs and symptoms that should be noted throughout the next few weeks and should be reported to your physician at once should they appear.

1. Unequal pupils
2. Blurred or double vision
3. Confusion
4. Disorientation
5. Drowsiness or impairment of consciousness
6. Headache
7. Vomiting
8. Irritability
9. Muscular weakness
10. Neck pain
11. Poor coordination
12. Stiff neck
13. Seizures

APPENDIX E
Brain Injury Discharge Instructions (Experimental Group)
Cognitive Dysfunction and Behavioral Changes

After a brain injury it is common for the patient to experience subtle deficits of memory, thinking, and learning. The deficits mentioned below can affect the patient's job performance, educational skills, and social behavior. These symptoms do not indicate a medical emergency. You do not need to consult your physician except for advice.

1. Short term memory deficits. (Example: Asks for breakfast one hour after having eaten.)
2. Decreased learning ability. (Example: Poor ability to learn new job skills.)
3. Diminished ability to think, reason, and use abstract thoughts. (Example: Difficulty with previously learned skills.)
4. Decreased ability to concentrate. (Example: Has difficulty focusing on one task for any length of time.)
5. Inappropriate word usage or word formation. (Example: Garbled speech, incorrect naming of objects.)
6. Neglect or denial of injured part of body. (Example: Failure to dress the left side of the body.)
7. Difficulty with multiple stimuli. (Example: Patient gets anxious or confused in busy environments.)
8. Self-centeredness. (Example: Preoccupation with own feelings and desires.)
9. Lack of initiative and motivation. (Example: Difficulty in doing anything without urging from others.)
10. Fluctuating levels of mood and emotion. (Example: Happy one minute, and crying the next.)
11. Lack of in-depth insight. (Example: Doesn't understand the consequences of own actions.)
12. Lack of awareness of condition. (Example: Unaware of difficulties with lost skills.)
13. Increased susceptibility to fatigue. (Example: Tires after minimal physical effort.)

APPENDIX F

Raw Data

<u>Subject</u>	<u>Group</u>	<u>Score</u>	<u>Age</u>	<u>Sex</u>	<u>Ed.</u>	<u>Relation</u>	<u>Exper</u>	<u>Invol</u>	<u>Occupation</u>
1	C	0	42	F	BD	wife	no	no	florist
2	C	2	38	F	HS	mother	no	no	sales
3	C	2	39	M	HS	father	no	no	laborer
4	C	2	47	F	HS	sister	no	no	none
5	C	3	46	F	Ot	sister	no	no	shoe repr
6	C	2	22	M	Ot	son	no	no	mat hndlg
7	C	1	70	F	HS	wife	no	no	retired
8	C	2	59	F	HS	daugh	yes	no	none
9	C	7	64	M	HS	son	no	no	retired
10	C	3	42	F	HS	gdaugh	yes	yes	none
11	C	4	31	F	BD	wife	no	no	clerk
12	E	16	19	F	HS	grlfr	no	no	factory
13	E	4	54	F	HS	grlfr	no	no	nurse aid
14	E	14	34	F	AD	daugh	yes	no	med sec
15	E	6	68	F	HS	wife	no	no	retired
16	E	16	31	F	AD	daugh	yes	no	RN
17	E	18	66	F	HS	sis/law	no	no	retired
18	E	11	62	F	HS	sis/law	no	no	retired
19	E	10	64	M	HS	broth	no	no	retired
20	E	9	36	F	HS	daugh	yes	yes	soc work
21	E	16	43	F	HS	moth	no	no	bus drvr
22	E	16	44	M	HS	fath	no	no	mach op
23	E	18	37	M	HS	son	no	no	technician
24	E	14	25	M	BD	son	no	no	sales
25	E	16	71	M	AD	husb	no	no	sales mgt
26	E	14	34	M	HS	son	yes	no	painter
27	E	12	32	M	AD	broth	no	yes	tree remvr
28	E	6	57	F	HS	moth	no	no	dietary
29	E	0	18	F	HS	grlfr	no	no	none
30	E	5	46	F	BD	moth	no	no	computer

APPENDIX G

2-26-92

Connie Pudee has permission to use
my videotape on Discharge Instructions
after brain injury in her master's thesis.

Mary Sanguinetti

Congratulations!

APPENDIX H

October 7, 1991

Gloria Freeman
FA Davis Company
1915 Arch St.
Philadelphia, PA 19103

Dear Ms. Freeman,

I am a registered nurse presently completing course work for a master of science in nursing (MSN). As part of my thesis I have referenced a diagram out of a textbook published by FA David Company. The diagram is on page 173 of the book Analysis and Evaluation of Conceptual Models of Nursing by Jacqueline Fawcett.

This letter is to request permission to reproduce that diagram as part of my thesis research.

Thank you for your consideration of this matter.

Sincerely,

Connie J. Pardee
723 Parchmount Ave.
Parchment, MI 49004-1738

10/15/91

*Permission granted for use
stipulated with the under-
standing that full credit
will be given to source.*

Permissions Coordinator

APPENDIX H

Betty Neuman, R.N., Ph.D.
Box 488
Beverly, Ohio 45715

Dear Ms. Neuman,


It was so delightful talking with you the other day. As I stated, I am in the final stages of completing my master's thesis, Evaluating family caregivers' ability to select appropriated care techniques following discharge instructions on post traumatic brain injury symptoms. I am writing to you for permission to reproduce in the thesis, The Neuman Systems Model diagram. This would be reproduced from Figure 1-3 on page 26 of your book, The Neuman Systems Model (1989). If you are willing to give permission, please sign on the line at the bottom of this letter and return it to me.

As we discussed on the phone, please include my name on the Neuman mailing list. I would be happy to discuss use of the Neuman Systems Model with anyone who may be using it.

I have been the Trauma Nurse Coordinator for three years. Prior to that I was an emergency nurse for 5 years, and also have nine years of experience in neurosurgical intensive care. I have included my business card with my work address and phone number.

Thank you for your assistance. I look forward to receiving the Neuman Newsletter.

Sincerely,


Connie J. Pardee R.N. M.S.N.(c), C.E.N.
723 Parchmount Ave.
Parchment, MI 49004

616-344-7434 (evenings)

I give my permission for Connie Pardee to reproduce for her thesis the diagram of the Neuman Systems Model from my book, The Neuman Systems Model, page 26.

Date 3/14/95 Name 

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