STRESS, UNCERTAINTY, AND INFORMATION NEEDS
IN FAMILY CAREGIVERS OF SEVERELY HEAD-INJURED ADULTS
BEFORE FINAL DISCHARGE FROM REHABILITATION SETTINGS

by

Jane M. Merkley

A thesis submitted in conformity with the requirements for the Degree of Master of Science, Graduate Department of Nursing Science, in the University of Toronto.

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Stress, Uncertainty and Information Needs in Family Caregivers of Severely Head-Injured Adults Before Final Discharge from Rehabilitation Settings

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ABSTRACT

This descriptive study identified the stress, uncertainty and information needs of family caregivers in adults with severe head injuries before final discharge home. Fifteen female and 5 male caregivers completed the Family Caregiver Uncertainty in Illness Scale, Caregiver Information Needs Questionnaire, and a Problem Checklist. They also responded to open ended questions about discharge concerns, sources of uncertainty and the impact of the head-injury on their lives. The findings provide considerable evidence that before discharge from rehabilitation caregivers are highly stressed. They reported disruptions in their health, marital relationships, social lives and finances. They found living with "changed persons" who displayed severe antisocial behaviors particularly burdensome. Head-injured fathers were described as aggressive toward their young children leading caregivers to fear they would be violent at home. Family caregivers felt uncertain, wanted help to learn the caregiver role, and needed discharge information related to symptom management.
I wish to express my sincere appreciation and gratitude to all of those who have helped me in the completion of this thesis. In particular, I owe a debt of thanks to my two co-chairs, Dr. Patricia McKeever and Susan Galloway who at every critical moment, gave so generously of their time and encouraged me to complete the thesis when I was beginning to lose hope. I will never be able to thank either of you enough.

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CHAPTER ONE

The Problem and Purpose

Head injuries, a common cause of severe disabilities in young and middle-aged adults often have significant repercussions on family caregivers (Moore, Stambrook, Gill, & Lubusko, 1992). Although caregivers do not suffer the direct effects of the injury, they are often left to carry the burden of its consequences (Grinspun, 1991). These consequences typically include profound physical disabilities, cognitive deficits, behavioral disturbances and characterological changes (Grinspun, 1991; Lezak, 1978; Livingston, Brooks & Bond, 1985; Oddy, Humphrey & Uttley, 1978; Thomsen, 1974).

Increasingly, and relatively soon after the injury, family members are expected to assume responsibility for long term care of the head-injured in their homes. This shift in the site of care delivery has occurred because of a scarcity of rehabilitation settings and a larger move to community based health care (Acorn, 1992, Feldman & Bedard, 1987; Frye, 1987; Gleckman & Brill, 1995). As a result, family caregivers are providing a multitude of interventions including: physical care, emotional support, behavioral management strategies, social and leisure activities,
and community integration skills (Dring, 1989; Feldman & Bedard, 1987; Livingston et al., 1985; Rogers & Kreutzer, 1984; Waaland, 1990).

Caring for head-injured persons at home is known to have an impact in the long term on the physical and emotional health of family caregivers (Brooks, Campsie, Symington, Beattie, & McKinlay, 1986; Livingston et al., 1985; Rosenbaum & Najenson, 1976; Thomsen, 1974). Caregivers have been reported to experience anxiety, depression, social isolation and an increase in physical symptoms in response to the unrelieved burden of care (Brooks et al., 1986; Livingston et al., 1985; Mauss-Clum & Ryan, 1981; Rosenbaum & Najenson, 1976; Thomsen, 1974; Panting & Merry, 1972; Romano, 1974).

At least to some extent, the family caregiver's stress is related to information deficits and uncertainty. Many family caregivers perceive themselves to have inadequate information and training to provide care to an individual with such complex health needs (Lezak, 1978; Livingston et al., 1985; Oddy et al., 1978; Panting & Merry, 1972; MacDonald, 1992). In addition, behavioural and characterological alterations are associated with more severe stress in caregivers than the extent of physical disabilities
Finally, considerable stress stems from worry about their relatives' future care needs and ultimate prognoses (Oddy et al., 1978).

According to Mishel (1981) the amount of uncertainty individuals have about illness events influences their stress levels and affects their ability to cope. Lazarus & Folkman (1984) make a similar claim about information needs. Unfortunately, health care professionals cannot resolve many of the long-term uncertainties associated with head injuries nor can they provide certain information about prognoses. However, it may be possible to relieve some of the early uncertainty and stress by providing information to family caregivers about the care the head-injured relative will require at home following discharge.

Most studies exploring family caregivers' experiences after a head-injury have focused on the initial acute hospitalization or months and years after the injury. Little is known about their experiences just prior to discharge from rehabilitation settings. This study was conducted to describe the extent of stress and uncertainty, and perceptions of information needs just prior to their relative's final discharge from rehabilitation settings.
Information gained through this research could be used by nurses to design optimal interventions to inform and support family members as they prepare to assume the caregiving role.

Review of Related Research

Prior to this investigation, no empirical research had been published about the uncertainty and stress experienced by family caregivers prior to head-injured relatives' final discharge from rehabilitation settings. Similarly, family caregivers' perceptions of important information related to providing care at home had not been described. In contrast, several studies about the long term impact of caring for a head injured person at home have been conducted. Most of these studies were quantitative in nature and were conceptualized using variations of the psychological stress/coping model. In particular, caregiver stress has been measured in terms of stressors and adverse outcomes such as burden or strain. The literature review is organized under the following headings: sources of family caregiver stress; effects of stressors on family caregivers; and the information needs of caregivers.

Sources of Family Caregiver Stress

The findings of several research studies suggest that the extent, stress or burden of caregiving is related to a number of
symptoms displayed by the head injured person. McKinlay, Brooks, Bond, Martinage, and Marshall (1981) examined caregiver burden in 55 family caregivers of severely head-injured adults in Scotland. Caregivers were interviewed 3, 6, and 12 months postinjury to elicit objective and subjective burden. Subjective burden, defined as the amount of psychological strain attributable to patient changes, was assessed with a 7-point rating scale. The mean subjective burden was 3.5 at each visit, with 70% (n=38) of caregivers reporting medium (3-4) or high (5-7) burden. Subjective burden was positively associated with aspects of objective burden such as emotional changes in the head-injured person, and subjective complaints and disturbed behaviour in the head-injured person at all interview times. Language functioning and the number or extent of physical problems were not related to subjective burden ratings at any time.

The behavioral and characterological alterations exhibited by the head-injured person repeatedly have been shown to be the greatest source of burden for family caregivers (Brooks & McKinlay, 1983; Lezak, 1978; Livingston et al., 1985; McKinlay et al., 1981; Oddy et al., 1978; Thomsen, 1974; Willer, Allen, Durnan & Ferry, 1990). These changes are less easily understood by caregivers and
are more difficult to handle than physical changes (Lezak, 1978; Rosenbaum & Najenson, 1976; Thomsen, 1974; McKinlay et al., 1981; Mauss-Clum & Ryan, 1981; Panting & Merry, 1972). The most burdensome changes are unacceptable, aberrant or asocial behaviour (Thomsen, 1974; Lezak, 1988; Livingston et al., 1985; McKinlay et al., 1981). These include, pathological laughter (Thomsen, 1974), sexual impulsivity (Lezak, 1988), anger outbursts (Panting & Merry, 1972) and physical violence (Lezak, 1978; 1988; McKinlay et al., 1981; Panting & Merry, 1972). Most researchers have concluded that these negative changes are the greatest impediments to successful family and community reintegration of the head-injured person (Ben-Yishay & Diller, 1981; Bond, 1979; McKinlay, et al., 1981; Oddy & Humphrey, 1980). Although these conclusions are persuasive they have questionable validity because most studies were limited by convenience samples and had methodological problems such as instrumentation with poor or untested psychometric properties.

Many researchers have shown that uncertainty about recovery from head injury also contributes to psychological stress in family caregivers. Novack, Bergquist, Bennett and Gouvier (1991) studied the distress related to uncertainty among 45 caregivers of severely head-injured individuals during the rehabilitation phase of
recovery and shortly thereafter. Based on clinical interviews with caregivers during the rehabilitation program, uncertainty about the future was found to be a major component of caregiver anxiety (p. 73). Caregivers' lack of experience with head-injured persons and the unpredictability of ultimate prognosis contributed to uncertainty. In a similar study, Oddy et al. (1978) examined family stressors at 6 and 12 month intervals. Twelve percent of the 54 caregivers identified their major stress was concern for the head-injured person's future. This concern included fears that the individual would sustain another injury, uncertainty about eventual recovery, and questions about long-term care.

Uncertainty and psychological stress have also been noted to be high at various transitional stages of the hospital experience, including discharge from the Intensive Care Unit and in the Rehabilitation Setting (MacDonald, 1992; McMillan, 1991; Novack et al., 1991). MacDonald (1992) investigated uncertainty in thirty caregivers during the first 72 hours of head-injury patients' admission to an intensive care unit and two days after transfer out of the Intensive Care Unit. Similarly, McMillan (1991) measured uncertainty in parents of head-injured children within 72 hours of their discharge from the Intensive Care Unit. Both McMillan (1991)
and MacDonald (1992) found that uncertainty, as measured by Mishel's Uncertainty in Illness Scale, was high. High scores in both samples were attributed to the overwhelming nature of the medical and prognostic uncertainties at this point in the post injury trajectory, the lack of information given to caregivers, and situational factors such as lack of familiarity with a head-injury illness experience. It is unknown, if high uncertainty persists to the period of discharge from a rehabilitation setting. However, Novack et al. (1991) found 7% of the family caregivers (n=45) were clinically anxious and 4% were clinically depressed around the time of discharge from the rehabilitation setting. These findings lend support to the idea that uncertainty and stress may increase in Family Caregivers at certain periods during hospitalization and persist to the discharge phase.

Social role changes have been found to increase psychological stress in family caregivers. In a comparative study (n=30), Rosenbaum and Najenson (1976) found that wives of head-injured Israeli war veterans (n=10) experienced greater role changes and distress than the wives of paraplegic veterans (n=6) and a control group (n=14). The women of the head-injured men reported a decrease in leisure time, fewer contacts with friends and greater
disruption of their marital relationships. They also felt less able to share household, childrearing and financial responsibilities with their disabled husbands. The increased responsibilities and loss of enjoyable social activities were associated with depressed moods in all wives of the head-injured veterans. The study is limited by the obvious cultural and situational differences between wives of injured war veterans in Israel and the North American wives of individuals head injured accidentally. However, Kozloff (1987) and Jacobs (1988) also found that American family caregivers of head-injured patients often assumed additional roles and responsibilities to compensate for the increased dependence of the injured person and decreased contact and support from those outside the family.

Caregivers have reported that they had been ill-prepared by health care providers to manage the problems that emerged after hospital discharge (Oddy et al., 1978). The most common dissatisfaction expressed by caregivers was the perceived inadequacy of communication between medical staff and themselves. Relatives frequently attributed their stress to insufficient information regarding their relatives' condition and prognosis. Their greatest need for information was an estimate of the future
course of personality and cognitive changes. Oddy's findings are similar to those of others (Panting & Merry, 1972; Thomsen, 1974; Livingston et al., 1985), who all found that caregiver stress was exacerbated by insufficient information, especially regarding prognosis and anticipated difficulties.

The long-term social consequences and a lack of social support are additional stressors for caregivers. Kozloff (1987) found that as postinjury time increases, caregivers' social networks decrease in size and increase in density. Caregivers assumed more and more functions in relation to the head-injured person, and had fewer contacts for their own support. Lezak (1978) reported that social isolation was a factor in increasing caregivers' stress, as evidenced by their reports of feeling trapped and isolated. Feelings of embarrassment and abandonment by friends and extended family seemed to exacerbate caregivers' sense of isolation (Lezak, 1978). Caregiving demands restricted the ability of caregivers to pursue work, friendships and hobbies, further aggravating feelings of isolation (Lezak, 1978, 1988; Liss & Willer, 1990). Lezak (1978; 1988) observed that caregivers' sense of isolation was accompanied by feelings of guilt and responsibility. They also feared social rejection when they considered divorcing their head-
injured spouses. Lezak's studies are limited since her observations were drawn primarily from working with family caregivers in a support group setting. In addition, her descriptions of family reactions were based on clinical impressions and observations rather than standardized indices of psychological distress.

In summary, the research provides useful information about the sources of stress in caregivers. In particular, the nature and extent of the disabilities, uncertainty about prognosis and anticipated difficulties, altered social roles and diminished support, and a lack of information constituted the stresses experienced by caregivers. Most studies reviewed however, have several limitations. They have been conducted either during the initial acute hospitalization or months or years after the injury. In addition, most studies had small sample sizes, methodological shortcomings and were conducted outside Canada. Some investigators reported that transitional stages of the head-injured persons hospitalization and recovery increased uncertainty and stress amongst caregivers (McDonald, 1992; McMillan, 1991; Novack et al., 1991). Little is known about the stressors experienced by family
caregivers at the time of initial discharge from rehabilitation settings to their homes.

**Effects of Stressors on Family Caregivers**

The stress of caring for a head-injured person consistently has been found to be associated with diminished psychological health. Clinically significant levels of depression or anxiety in caregivers have been documented during the first year after a relative's head injury (Livingston et al., 1985; Mauss-Clum & Ryan, 1981; Oddy et al., 1978; Panting & Merry, 1972; Rosenbaum & Najenson, 1976). Livingston et al. (1985) noted that one third of relatives (N=57) reported high levels of anxiety, and one fourth were considered depressed. Oddy et al. (1978) found that 39% of caregivers (N=54) were significantly depressed 1 month after the injury, and 25% remained depressed at 6 and 12 months postinjury. Furthermore, caregivers in two of these studies reported taking anti-depressants or minor tranquillizers on a regular basis whereas non had required these medications before the injury (Oddy et al., 1978; Panting & Merry, 1972). Neither anxiety nor depression were associated with how long the patient had been hospitalized, the degree of physical disability or the severity of the head injury.
Caregivers with continuous anxiety and depression have been noted to have an increased susceptibility to physical symptoms such as decreased energy (Lezak, 1978; 1988), headaches (Brooks et al., 1986), disruption in eating and sleeping (Mirr, 1991; MacDonald, 1992), and fatigue (Lezak, 1978; 1988). The relationship between caregiving and poor physical health was examined in a prospective study of 54 closed head injury patients (Oddy et al., 1978). Caregivers were interviewed within a month of the injury and again six and twelve months later. At six and twelve months about 25 percent of the caregivers experienced illnesses such as asthma, migraine, headaches and gastrointestinal ulcers.

Providing home care to head-injured persons has disruptive effects on family life and social functioning. Disintegration of sibling (Oddy & Humphrey, 1980), parent-child (Thomsen, 1984; Lezak, 1988) and marital relationships (Lezak, 1988; Livingston et al., 1985; Mauss-Clum & Ryan, 1981; Oddy et al., 1978; Panting & Merry, 1972; Willer et al., 1990; Hall, Karzmark, Stevens, Englander, O’Hare, & Wright, 1994) have been attributed mainly to the behavioral and characterological changes in the head-injured person. Rosenbaum and Najenson (1976) found that most head injured persons (N=30) participated minimally in households tasks and child
care. The family caregivers had less leisure time and spent less time with relatives. They met with old friends less frequently, a significant social loss to wives.

In summary, the effect of caregiving for head-injured relatives is characterized by severe stress (Brooks et al., 1986; Haberman, 1982; Livingston et al., 1985; Mauss-Clum & Ryan, 1981; Oddy et al., 1978). The experience of caregiving is associated with negative emotional states, physical health problems and disrupted social lives and family relationships.

The Information Needs of Family Caregivers

Most investigations of information needs of family caregivers of persons with head injuries have focused on the initial acute period of hospitalization (Leske, 1986; Mathis, 1984; Mauss-Clum & Ryan, 1981; Mirr, 1991; Molter, 1979). However, adequate caregiver education is identified as an important factor which promotes successful rehabilitation outcomes for head-injured persons and promotes family well-being (Johnson & Higgins, 1987; Thomsen, 1974; Kreutzer, Zasler, Camplair, & Leininger, 1990).

Campbell (1988) examined the educational needs of caregivers (N=14) during the post-hospital phase of recovery using a questionnaire designed to determine caregiver needs. The
respondents were attending a support group and most were mothers of young men. Subjects were asked to identify their needs from a list of education, emotional, and social support needs. All subjects wanted their questions answered adequately and honestly by health care professionals and to learn about the effects of head injury, physical care, methods of adjusting to the patient's memory loss and behavioral changes, financial assistance, and community resources. The validity of Campbell's findings are limited by a low rate of responses to the questionnaire (19 percent) and by the use of convenience sampling. Further, the time frame post recovery that these respondents were at is unknown.

The importance of discharge teaching for family caregivers was demonstrated by Sanguinetti and Catanzaro (1987). They used an experimental design to examine the effects of discharge teaching on the ability of 29 relatives to apply information in simulated patient care. Information about the physiological complications and cognitive changes associated with head injuries were identified as important for caregivers to know upon discharge from hospital. Both control and experimental groups received routine discharge instruction about the physiological complications following head injury. The experimental group watched an additional videotape on
cognitive dysfunction. The results indicated that there was a significant difference in caregivers' ability to extrapolate appropriate patient care techniques after receiving cognitive dysfunction instruction. The researchers concluded that caregivers in the experimental group were better prepared to help head-injured persons to compensate for cognitive dysfunctions. The findings did not include the effects of discharge teaching on family outcomes or what caregivers themselves identified as important information needs.

In summary, research findings indicate that caregivers require information following a relative's head injury (Sanguinetti & Catanzaro, 1987; Campbell, 1988). However, little is known about the specific discharge information needs caregivers' perceive as helpful. Knowledge of such needs is essential to design effective interventions to assist caregivers to adjust to their new roles and provide optimal care.

Conclusion

The research conducted prior to the present study about family caregivers of head-injured relatives revealed the nature of and responses to the stresses involved in caregiving. Clearly, the nature and extent of the disabilities, uncertainty about prognosis
and anticipated difficulties, altered social roles and support, and lack of information contribute to the stress felt by caregivers. Further, physical and psychological problems and disrupted social support and family relationships are common. These findings may not be generalizable to the present study population because of sampling issues, they were conducted during a different point in the recovery trajectory, and occurred in non-Canadian settings.

Information had been identified as an important mediating factor in diminishing stress by helping caregivers prepare for the caregiving role and adjust to the illness experience. There was, however, no documentation about the perceived information needs in caregivers immediately prior to their head-injured relative's discharge from the rehabilitation setting. Therefore, it was important to examine the stress, uncertainty, and information needs of family caregivers with a head-injured relative at this point in the injury trajectory.

Conceptual Framework

The conceptual framework for this study is based on two theoretical perspectives, the theory of Stress, Appraisal and Coping by Lazarus and Folkman (1984) and Mishel's Theory of
Uncertainty in Illness (Mishel, 1988). These theories provide a framework for understanding the interrelationships and responses of people to stressful life events, such as a head-injury in a relative. Lazarus and Folkman (1984) believe that stress is neither a stimulus or a response but a transaction between the person and the environment in which the internal or environmental demands, tax or exceed the person's resources. In this transactional relationship, cognitive appraisal occurs in response to any event. Cognitive appraisal is a mental process whereby an event is evaluated as being irrelevant, benign or stressful (Lazarus & Folkman, 1984). Once a situation is judged as being stressful, it is then appraised to be a harm/loss, threat or challenge. Lazarus and Folkman (1984) postulate that how well a person copes with a stressful situation depends partially on his or her individual's cognitive appraisal of the situation. In this light, the event of a head-injury in a relative may be appraised as threatening as it produces the potential for harm or loss (Lazarus & Folkman, 1984, p.32).

Caregivers' responses to head injury in a relative may be understood more fully by exploring factors impinging on the appraisal process (MacDonald, 1992). According to Lazarus and
Folkman (1984) there are many personal and environmental factors that influence a person’s ability to appraise a situation. Some of the most important person factors are one’s commitments and beliefs. Novelty, predictability and event uncertainty are examples of environmental factors that influence how situations are appraised (Lazarus & Folkman, 1984). Mishel’s Theory of Uncertainty expands on how event uncertainty may affect appraisal in illness situations (Mishel, 1988).

According to Mishel (1988) uncertainty exists when an individual is unable to determine the meaning of illness-related events. It is "the cognitive state created when the person cannot adequately structure or categorize an event because of lack of sufficient cues" (Mishel, 1988, p. 225). Uncertainty arises when illness experiences are unfamiliar, complex and unpredictable. Mishel (1988) indicates that in illness situations, perception of uncertainty is influenced by such factors as: the unpredictability of symptoms, familiarity with the illness outcomes and the cognitive abilities of the person.

The experience of caring for a head-injured person is characterized by feelings of uncertainty because relatives’ symptoms are often severe and inconsistent. Further, the course of
recovery from head injury is variable and unpredictable. Therefore, caregivers may perceive the situation as threatening because unknown losses are still to come in the course of the patient's recovery. At the time of discharge from the rehabilitation setting, uncertainty may increase as the caregiver prepares to assume the responsibility for meeting complex care needs at home. Further, the caregiving situation represents many unknown alterations, both temporary and permanent, in the life of the caregiver.

Uncertainty hampers the appraisal process because the person is unable to form an accurate cognitive schema for the illness-related events and therefore is unable to interpret what is happening. Information may be used by caregivers to form a framework to order the illness-related experience (Mishel, 1988) and enhance cognitive comprehension of an event (Lazarus & Folkman, 1984, p. 85). Gaining information may, therefore, reduce uncertainty and enhance the caregiver's understanding of an illness event (Galloway & Graydon, 1996). It allows the person to understand the event and form realistic plans to deal with the event. Many personal and environmental factors account for individual differences in the way people deal with situations.
Consequently, family caregivers' requirements for information at the time of discharge from rehabilitation may vary from caregiver to caregiver.

In summary, the head-injury experience is highly conducive to feelings of uncertainty and stress appraisals for family caregivers. Most family caregivers face a catastrophic injury which they have never had to deal with before and thus are unprepared about what to expect. The discharge of the head-injured patient from hospital may be a particularly stressful period with many uncertainties for family caregivers. The caregiver enters a new and unique situation and may appraise the situation related to his/her new role as stressful. Some of the uncertainty felt by caregivers may be related to the perception that they lack information about their situation (Campbell, 1988; Mathis, 1984; Mauss-Clum & Ryan, 1981; Mirr, 1991). Conceptually, caregivers may need information in situations of uncertainty. However, no studies have examined the stress, uncertainty or information needs at the time of discharge from hospital. This framework shaped the design of this study and the analysis of the findings.
Assumptions

The study was based on the assumption that caregivers would be able to describe their stress, uncertainty and information needs prior to their relatives discharge from the rehabilitation setting.

Research Questions

This research study was designed to answer the following questions regarding the family caregivers' experiences just prior to the head-injured person's discharge from the rehabilitation setting.

1. What stresses do family caregivers identify just prior to discharge?
   a) Which symptoms of the head-injured person do family caregivers perceive as stressful?
   b) Which symptoms of the head-injured person do family caregivers perceive to cause the greatest amount of stress?
   c) What other stressors were identified by family caregivers?

2. What effects do these stresses have on the family caregivers?

3. a) What level of uncertainty is experienced by family caregiver at the time of discharge?
   b) What causes the most uncertainty for family caregivers?
4. What information needs do caregivers perceive as being the most important at the time of discharge?
CHAPTER 2

Design and Methods

Research Design

A descriptive exploratory design was used to describe stress, uncertainty, and information needs in family caregivers of head injured patients at the time of discharge from the rehabilitation setting. A combination of qualitative and quantitative techniques was used.

Setting

Data collection occurred in the head injury rehabilitation units of two Canadian urban teaching hospitals over a 6 month period in 1992. These settings provide programmes designed to assist the victims of head injury to reduce or adjust to their functional deficits, and to assist them and their family caregivers to attain the skills needed to function as independently as possible in the community. None of the head-injured relatives had cognitive or physical disabilities prior to the head injury.

Sample Selection

A non-probability, convenience sample of family caregivers for 20 severely head-injured patients was obtained. Caregivers were family members, or spouse/partners of head-injured persons who
identified themselves as the primary caregiver. All caregivers in this sample:
1. were able to read, speak and write English.
2. were able to provide consent to participate in the study.
3. were between 18 and 80 years of age.
4. were interviewed within 7 days of planned hospital discharge.

**Instrumentation**

Data collection was carried out using five instruments: the Caregiver Information Needs Questionnaire (CINQ); the Family Caregiver Uncertainty in Illness Scale (FCUIS); the Problem Checklist for Family Caregivers (PCL-FC); the Patient Demographic and Pre-Injury Form (PD-PIF) (Appendix A); and the Family Caregiver Demographic Sheet (FCDS) (Appendix B).

**Caregiver Information Needs Questionnaire (CINQ)**

Caregivers' perceptions of what is important to know in relation to the care of a head-injured relative was measured by the CINQ, a modified version of the Patient Learning Needs Scale (PLNS) developed by Bubela and colleagues (1990b). The CINQ consisted of 30 items from the PLNS, eight items from the Family Needs Questionnaire (Kreutzer et al., 1990) (items 17, 20, 22, 27-29, 35, and 44 of the CINQ) and 10 items developed by the investigator.
specific to traumatic head injury (items 5-7, 16, 21, 37, 40, 47-49 of the CINQ).

The PLNS (Bubela et al., 1990a) was developed to measure the perceived importance of information in medical-surgical patients. It was chosen as a basis for the CINQ because: it is based on a similar theoretical framework as this study; it measures learning needs prior to discharge from an institutional setting to home; it covers broad areas of illness concerns; and is easily understood by respondents. The PLNS examines the subject's perceived importance of discharge information needs in relation to medication administration; guidelines for physical activity, rest, sleep and nutrition; availability of health care services in the community; recognition and expression of feelings associated with the illness; understanding the purpose of treatments and recognition of possible complications; management of symptoms; and caring for the integument (Bubela et al., 1990b). The CINQ differs from the PLNS in that it also investigates caregivers' perceived importance of specific information related to caring for a head injured patient.

The CINQ has 50-items, and is self-administered. It examines perceived importance of information in relation to all of the major areas on the PLNS except skin care. One item from this subscale was
retained and added to the "treatment and complications" subscale (item # 45 on the CINQ). Subjects are asked to rate each item in terms of its importance for the management of the head-injured patient's care at home. Responses to each question on the CINQ is rated on a scale: 1 (of no importance) to 5 (extremely important). The scale yields a total and six subscale scores.

Face and content validity of the CINQ were established by developing an item pool from previous research findings, personal clinical experience, items from the PLNS and Family Needs Questionnaire and discussions with three nurse experts. Items were examined and rewritten into 61 items to apply to the head-injured population. Based on comments received from the nursing experts, the wording of several items were altered to increase clarity, one item was deleted and 5 items were added. The revised item list was then shown to 3 nursing professors as a further check of face validity. From the 65 items, six items related to symptomatology were eliminated due to their similarity to items on the PCL-FC form and five general items were omitted because they were not relevant to the head-injured population. To provide some assurance that the integrity of the original PLNS had not been violated, the investigator and a colleague independently categorized each
question by the six retained subscale titles of the PLNS. Agreement was obtained for over 90% of the questions according to all six domains. The remaining 10% of the questions were revised and rechecked until consensus was obtained.

Although the original PLNS had high internal consistency reliability with Cronbach's alpha of .95 (Bubela et al., 1990b), the CINQ reliability was not established prior to this study. The internal consistency reliability of the CINQ was assessed prior to data analysis with Cronbach's alpha. When used with caregivers of head-injured persons, the CINQ had good internal consistency reliability with a Cronbach's alpha of .93 for the total scale, and Cronbach's alpha of .69 to .85 for each of the six subscales.

Family Caregivers' Uncertainty

Uncertainty, the person's inability to determine the meaning of illness related events (Mishel & Epstein, 1990), was measured by the Family Caregiver Uncertainty in Illness Scale (FCUIS) (Brock, 1990), a modified form of the Parent's Perception of Uncertainty Scale (Mishel, 1983). According to Mishel and Epstein (1990) this instrument can be modified to measure any family member's uncertainty by changing the wording of the questions to
reflect the relationship, e.g., "I don't know what is wrong with my spouse". It has been used in a variety of clinical populations.

The FCUIS is a self-administered, 31-item, 5-point Likert-type scale that taps the uncertainty that family caregivers experience concerning a family member’s illness (Mishel & Epstein, 1990). Individual item scores range from 1 to 5, higher scores represent more uncertainty or unpredictability. The FCUIS has been factor-analyzed into a four factor scale, however for the purposes of this study only the total score was used as the measure of uncertainty.

The internal consistency reliability of the total scale and each factor has been reported as satisfactory with total scale coefficient alphas of .71 to .91. (Mishel & Epstein, 1990). Construct validity of the FCUIS has been noted when Mishel (1983) found that the FCUIS scores in a sample of 272 parents were able to discriminate medical, surgical and diagnostic groups. The parents of children receiving medical treatment were more uncertain when compared to parents of children receiving surgical treatment although no significant differences in level of uncertainty between the medical and diagnostic groups emerged. A probe question (see
Appendix C, #1) was used to obtain additional data about uncertainties felt by family caregivers.

The Problem Checklist for Family Caregivers

The PCL-FC is one part of the Head Injury Family Interview (HIFI) developed to describe the recovery patterns from traumatic head injury (Kay, Cavallo & Ezrachi, 1988). The HIFI consists of four sections plus a demographic and pre-injury function section. The PCL-FC measures the level of stress family caregivers feel as a result of symptoms in head-injured persons. It has been used in outpatient settings with families of adults and children with head injuries of varying severity (Rivara, Fay, Jaffe, Polissar, Shurtlaff, & Martin, 1992; Cavallo, Kay & Ezrachi, 1992).

The PCL-FC of Version 1.2 of the HIFI used in this study consists of a list of 34 physical, cognitive, behavioral and affective symptoms that are common in head-injured persons after traumatic head injury. The caregiver is asked to rate how much of a problem each symptom presents in the head-injured patient's daily functioning on a Likert scale ranging from 1 to 7. On a similar scale, caregivers are asked how much strain they feel as a result of this problem. If the respondent reports that symptoms are absent, a score of one on the Likert Scale is obtained to
facilitate data analysis. For the purpose of this study, the symptoms described by the family caregiver as problematic in the head-injured person's daily functioning and those described as causing a strain were defined as stressors influencing the appraisal process.

Ratings between 2 and 7 on the problem scale were considered an endorsement of a symptom. The strain responses were considered along the full range (Cavallo et al., 1992). The PCL-FC has no reported reliability and validity, although it is currently being field tested in a multi-center study.

**Patient Demographic and Pre-Injury Form**

The PD-PIF was developed by Kay et al. (1988) as a portion of the HIFI, to collect demographic and preinjury data about the head-injured person (Appendix A). It is to be completed from the most reliable information available, either the subject's medical record or from significant others. The PD-PIF, in its original form, is divided into three sections: Demographic Information, Accident/Medical Information, and Pre-Accident Information. The Pre-Accident Information data were not collected as they did not relate directly to the research questions being asked.
The section on Demographic Information was altered slightly. Date of birth was changed to age, ethnic status was replaced with an open-ended question asking subjects which culture they felt most closely associated with and date of injury was expanded to include information about: about length of stay in acute and rehabilitation hospitals, cause of head injury, diagnosis upon admission, whether the patient been home on a week-end pass, and the availability of discharge community supports.

The severity of the head injury was measured by the length of post-traumatic amnesia, duration of coma and the admission Glasgow Coma Score (GCS). Post-traumatic amnesia (PTA) was defined as the time interval between the injury and the beginning of continuous day-to-day memory, (Fortuny, Briggs, Newcombe, Ratcliff, & Thomas, 1980; Teasdale & Jennett; 1974; Jennett, 1976) and is one of the best indicators of the severity of brain damage (Schwartz, Sharkey & Andersen, 1991). A PTA time of over 48 hours is indicative of a severe head injury and over 7 days is very severe head injury (Oddy et al., 1978; Livingston et al., 1985). The period of coma, defined as a GCS score of less then eight for a period of time exceeding 24-hours (Kay et al., 1988), is considered to be a less sensitive guide to the severity of injury (Panting & Merry, 1972).
The GCS score, is also used as a method for classifying severity of head injury (Teasdale & Jennett, 1974). It may, however, be a less sensitive index than the PTA as it is affected by many factors such as alcohol and drug consumption and traumatic injuries to the face. The GCS is useful as it is routinely documented on admission to hospital and easily obtained.

The GCS score is determined by the patient's best eye opening response, best motor response, and the best verbal response. The numerical values of each subscale are added to produce a composite score. The scores range from 3 to 15, with higher scores indicating less injury. The severity of head-injury is generally considered severe if the subject has a GCS of 8 or less (after trauma resuscitation), moderate if it is between 9-13, and mild if it is greater than 13 (Teasdale & Jennett, 1974).

**Family Caregiver's Demographic Sheet (Appendix B)**

The Family Caregiver's Demographic Sheet consisted of 6 items, adapted from the HIFI-Significant Other Interview and portions of the Demographic and Pre-injury Form developed by Kay et al. (1988). Demographic items included the subject's sex, educational level, relationship to the patient, ethnicity, employment status, and how well the subject was acquainted with patient's behaviour.
Exploring Family Caregivers' Experiences

Qualitative data were elicited using The Family Caregiver’s Experience: Open-Ended Question Sheet (Appendix C). Open-ended questions were developed to capture the experience of stress and uncertainty at the time of the head-injured relative’s discharge from hospital. Questions concerning the impact of the head injury on the caregiver were adopted from the "Impact on the Family Interview" of the Head Injury Family Interview (Kay et al., 1988). Such data were gathered to provide a picture of additional aspects of the caregiver’s stress experience. Subjects were asked the questions by the researcher who recorded responses in a notebook. The caregivers own wording was used whenever possible.

Pretesting

A pretest of the data collection methods was conducted on the first five subjects for comprehension, ease, clarity, and timing. As there were no problems with the clarity of the instruments, and/or data collection methods, these pre-test data were used in the final data analysis.

Data Collection Methods

The researcher met with family caregivers who had consented to participate in the study within 7 days before the head-injured
patient’s discharge date. A private area of the ward was used for the interview. Questions about the study were answered prior to the randomly ordered administration of the instruments. Following completion of the CINQ, FCUIS, PCL-FC, PD-PIF and PCDS, an opportunity was provided to answer any questions the participants had regarding the data collection process. Open-ended questions were asked at the conclusion of the interview to obtain qualitative data concerning the subject’s experiences of stress and uncertainty. The researcher then completed the portion of the PD-PIF that required data from the patient’s charts.

Protection of Subjects

Approval to conduct the study was obtained from the Office of Research Services at the University of Toronto, and from the Research committees at the participating hospitals. Hospital delegates (nurse educator and social worker) identified patients who met the sample inclusion criteria and obtained verbal approval for the investigator to contact them (Appendix D). Once verbal permission was granted, potential subjects were approached by the investigator. An explanation of the study, including its purpose and time commitment, and an opportunity for questions were provided (Appendix E). Subjects were assured that that data would be kept
confidential, that participation in the study was voluntary and could be terminated at any point in time, and that withdrawal from the study would not affect the care they or the patient received. Subjects were given a complete description of the methods of collecting and recording the data. They were also informed that they would not personally benefit from the study but that their involvement might assist health professionals in improving the care provided to other head-injured patients.

Subjects were assured that they would not be identifiable in the written documentation of the data collection process, discussions, or publications. Code numbers were assigned to each questionnaire and demographic sheet, thereby eliminating the use of subjects' names. A master list of subjects' names with their corresponding code numbers, consents, and all data will be kept in a locked drawer for six years. Subjects were assured that data would only be available to the researcher and her thesis committee members. Following these assurances, written consent was obtained (Appendix F).

Data Analysis

After completion of data collection, all coded and scored data were entered in the computer for statistical analysis using the
CRUNCH statistical program. Data analysis included examining the psychometric properties of all instruments using Cronbach's alpha, describing the sample, and answering each research question. The alpha level for determining statistical significance was set at 0.05 for all tests. Descriptive statistics were used to describe the characteristics of the caregivers and their relatives.

Content analysis of the responses to the open-ended questions, was carried out to gain further insight into the experiences of stress and uncertainty among caregivers. A phrase-by-phrase analysis of the responses to the open-ended questions was done to describe general categories of stress, concerns, and uncertainty that were described by caregivers. Within each general category similar responses were grouped into sub-categories, and sub-category definitions were developed. Concurrent with this process, literature was reviewed to assist in generating the sub-category definitions. Phrases in each category were then ranked according to their frequency of occurrence.

Upon completion of the content analysis, a random selection of five interviews, was examined by a colleague who classified responses into the defined categories. The results from the grouping were compared by the two raters for similarities and
differences. The level of agreement between the investigator and this colleague was 80%, suggesting the need to revise the categorization scheme and refine the sub-category definitions. After some discussion and a change in the words to better describe the categories and definitions, consensus was reached for all remaining responses.
CHAPTER THREE

The Findings

Quantitative and qualitative findings will be presented under the following headings: a) description of head-injured persons and family caregivers, b) stresses family caregivers identify just prior to head-injured persons’ discharge from the rehabilitation settings, c) the effects these stresses have on family caregivers, d) family caregivers’ experiences of uncertainty at the time of discharge, and e) family caregivers’ perceptions of important discharge information.

Description of Head-Injured Persons and Family Caregivers

Twenty-four subjects who met the inclusion criteria were approached by the researcher regarding the study. Of these, twenty-one subjects consented and twenty actually participated in the study. Three subjects declined to participate after receiving detailed information about the study. Reasons given included being “too upset” (n=1), “too stressed to talk” (n=1) and having “too many demands” on their time (n=1). One additional subject, a male, withdrew after completing two questionnaires citing time constraints. All subjects were interviewed within 1 week prior to the head-injured relative’s discharge from the rehabilitation
setting. The time required for the interviews ranged from 20 minutes to 2 hours with an average of about 1 hour.

As illustrated on Table 1, three-quarters of the head-injured patients were less than 50 years old. The total sample consisted of 12 males and 8 females ranging in age from 21 to 80 years (Mean =39.5). Fifteen patients were Canadian born, two were Chinese, and three were Italian, Yugoslavian or Portuguese immigrants respectively. At the time of the interview, one-half of the patients were married (n=9) or living common-law (n=1), and the remainder were single (n=8), separated (n=1), or widowed (n=1).

Table 1

Distribution of Head-Injured Patients by Age and Sex

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>Males</th>
<th>Females</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>21-30</td>
<td>5</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>31-40</td>
<td>2</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>41-50</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>51-60</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>61-70</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>71-80</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Totals</td>
<td>12</td>
<td>8</td>
<td>20</td>
</tr>
<tr>
<td>Mean Age</td>
<td>36.9</td>
<td>40.9</td>
<td>39.5</td>
</tr>
<tr>
<td>SD</td>
<td>14.5</td>
<td>21.2</td>
<td>16.8</td>
</tr>
</tbody>
</table>
Interestingly, after their injuries two patients had been reunited with their separated spouses. Reasons given by the caregivers for this change were obligation to their spouses and convenience for caregiving. Prior to their injuries, most patients had been working either full-time (n=9) or part-time (n=3), while four were students, and four were homemakers, retired or unemployed.

The majority had been involved in some form of motor vehicle accident (n=17). Other causes of injury were falls (n=1), industrial accidents (n=1), and assaults (n=1). Alcohol and/or other drug use by the patient prior to the injury had been confirmed by blood levels in 3 cases and documented as strongly suspected based on social histories in 5 others.

Eleven subjects had been admitted with primary diagnoses of severe closed head injury (CHI) and nine with severe multiple trauma including CHI. Glasgow Coma Scale scores on admission to hospital ranged from 3 to 14. The median and modal GCS scores was 6 and 3 respectively. Fifteen of the head injuries were classified as severe with admission score of 8 or less. The period of coma, ranged from 1 to 56 days (= 7.5, SD=12.7). The duration of post traumatic amnesia (PTA), ranged from 1 to 550 days (= 80.1, SD=
Seventeen patients had a PTA of greater than 1 week, indicative of very severe head injury. See Table 2 for a description of the injury related characteristics.

Table 2

Injury Related Characteristics: Frequency Distributions n=20

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Frequency</th>
<th>Characteristics</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Glasgow Coma Scores</td>
<td></td>
<td>Neurologic Diagnoses</td>
<td></td>
</tr>
<tr>
<td>3-8 (severe)</td>
<td>15</td>
<td>Diffuse axonal injury</td>
<td>2</td>
</tr>
<tr>
<td>9-12 (moderate)</td>
<td>3</td>
<td>Cerebral edema</td>
<td>2</td>
</tr>
<tr>
<td>13-15 (mild)</td>
<td>2</td>
<td>Intracranial hemorrhage</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Contusional hemorrhage</td>
<td>4</td>
</tr>
<tr>
<td>Length of PTA (days)</td>
<td></td>
<td>Edema, contusion + hem.</td>
<td>4</td>
</tr>
<tr>
<td>&lt;48 hrs</td>
<td>1</td>
<td>No lesion</td>
<td>2</td>
</tr>
<tr>
<td>3-7</td>
<td>2</td>
<td>Operative Procedures</td>
<td></td>
</tr>
<tr>
<td>8-40</td>
<td>7</td>
<td>No surgery</td>
<td>9</td>
</tr>
<tr>
<td>41-60</td>
<td>4</td>
<td>Evacuation of hemorrhage</td>
<td>3</td>
</tr>
<tr>
<td>61-80</td>
<td>1</td>
<td>ICP monitor + evacuation</td>
<td>3</td>
</tr>
<tr>
<td>81-100</td>
<td>1</td>
<td>ICP monitoring device</td>
<td>2</td>
</tr>
<tr>
<td>100+</td>
<td>4</td>
<td>Removal of contused or necrotic brain tissue</td>
<td>1</td>
</tr>
<tr>
<td>Duration of Coma (days)</td>
<td></td>
<td>ICP monitor + evacuation + removal of tissue</td>
<td>1</td>
</tr>
<tr>
<td>&lt;24 hrs</td>
<td>7</td>
<td>ICP monitor + removal of bone flap</td>
<td>1</td>
</tr>
<tr>
<td>2-20</td>
<td>11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>21-40</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>40-60</td>
<td>1</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

In addition to the head injury, the patients generally had a number of abrasions and lacerations. The multiple trauma patients had all been critically ill, with orthopaedic injuries (including facial fractures), and injuries to the chest and internal organs.
One patient had sustained permanent blindness and two had lost a limb as a result of their accidents.

The length of stay in the acute care setting ranged from 17 to 910 days (Mean=116.9, SD=211). When the 3 subjects hospitalized for greater than 155 days were withdrawn, the number of hospital days ranged from 17 to 85 days (Mean=42.4, SD=23.5). The mean length of time spent in the rehabilitation unit was 104.1 days, with a range from 27 to 528 days. However, after elimination of 4 subjects with extremely long stays, the range was 27 to 95 days (Mean=53.1, SD=18.3). The total time spent in hospital ranged from 54 to 1137 days (Mean=227.5, SD=313.2). The range without the two extreme high scores was 54 to 335 days (Mean=117, SD=31.2).

A total of 20 family members, 15 women and 5 men, who expected to be primary caregivers after discharge were interviewed. Their characteristics are displayed in Table 3. The majority of the caregivers considered themselves to be Canadian (n=18) and 2 were Chinese. The majority (n=17) of the caregivers described themselves as well or very well acquainted with their relative's current behaviour and abilities. Most patients had been taken home on week-end passes since the early period of the rehabilitation process (n=19) and all had been home at least twice prior to
Table 3.

Frequency Distributions of Sociodemographic Characteristics of Caregivers

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Frequency (n=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Relationship to Patient</strong></td>
<td></td>
</tr>
<tr>
<td>Wife/Common-law</td>
<td>8</td>
</tr>
<tr>
<td>Mother</td>
<td>4</td>
</tr>
<tr>
<td>Daughter</td>
<td>3</td>
</tr>
<tr>
<td>Husband</td>
<td>2</td>
</tr>
<tr>
<td>Male Partner</td>
<td>2</td>
</tr>
<tr>
<td>Father</td>
<td>2</td>
</tr>
<tr>
<td><strong>Employment Status</strong></td>
<td></td>
</tr>
<tr>
<td>Working, Full-time</td>
<td>9</td>
</tr>
<tr>
<td>Homemaker</td>
<td>5</td>
</tr>
<tr>
<td>Working, Part-time</td>
<td>3</td>
</tr>
<tr>
<td>Unemployed</td>
<td>2</td>
</tr>
<tr>
<td>Retired</td>
<td>1</td>
</tr>
<tr>
<td><strong>Education Level</strong></td>
<td></td>
</tr>
<tr>
<td>College or University</td>
<td>10</td>
</tr>
<tr>
<td>High School</td>
<td>8</td>
</tr>
<tr>
<td>Graduate School</td>
<td>4</td>
</tr>
</tbody>
</table>

discharge. All were expected to receive some form of out-patient rehabilitation one to three times per week. The most frequently cited services were physical therapy, occupational therapy, speech therapy, vocational rehabilitation and psychological counselling.
Stresses Identified by Family Caregivers

In order to examine what stresses family caregivers identified prior to the head-injured person's discharge from the rehabilitation setting, the Problem Checklist-Family Caregiver Instrument (PCL-FC) and qualitative data from questions 2 and 3 (Appendix C) were analyzed. Family caregivers' perceptions of problematic symptoms displayed by the head-injured person, as measured by the PCL-FC, were considered stresses affecting family caregivers. As suggested by Cavallo et al. (1992), to determine which symptoms were perceived by family caregivers to be most problematic, only symptoms rated between 2 and 7 were retained. In addition a list of symptoms reported by 70% or more of the caregivers were identified (see Table 4) with their mean strain scores. All symptoms on the PCL-PC, their frequencies and mean strain scores are listed in Appendix G. The 10 items on the PCL-PC with the highest mean scores for caregiver strain are presented in Table 5.

In order to elicit additional data about stresses, family caregivers were asked to identify areas that they felt most concerned about before taking their head-injured relative home and to describe the impact that the head-injury had had on their lives.
Table 4.

Symptoms Perceived by 70% of Caregivers as Problematic and Caregiver Mean Strain Scores (n=20)

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Frequency</th>
<th>Mean Strain*</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impatience</td>
<td>18</td>
<td>3.75</td>
<td>2.0</td>
</tr>
<tr>
<td>Dependency on Others</td>
<td>16</td>
<td>3.90</td>
<td>2.6</td>
</tr>
<tr>
<td>Being forgetful</td>
<td>15</td>
<td>3.10</td>
<td>2.1</td>
</tr>
<tr>
<td>Fatiguing quickly</td>
<td>14</td>
<td>2.50</td>
<td>1.8</td>
</tr>
<tr>
<td>Irritability</td>
<td>14</td>
<td>3.05</td>
<td>2.1</td>
</tr>
<tr>
<td>Changed Personality</td>
<td>14</td>
<td>3.40</td>
<td>2.5</td>
</tr>
</tbody>
</table>

*Possible ranges of scores on individual items is 1 to 7

Responses were grouped and labelled as: Living and Dealing with the Changed Person; Additional Responsibilities and Altered Family Roles; and Lack of Information, Professional Support and Community Resources. Although the examples of the categories often came from the most articulate family caregivers, all caregivers' perspectives contributed to the analysis. Appendix H summarizes the additional stresses identified by caregivers.
Table 5

Head-Injured Person's Symptoms Causing High Strain for Family Caregivers

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Mean Strain*</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dependency on Others</td>
<td>3.90</td>
<td>2.6</td>
</tr>
<tr>
<td>Impatience</td>
<td>3.75</td>
<td>2.0</td>
</tr>
<tr>
<td>Changed Personality</td>
<td>3.40</td>
<td>2.5</td>
</tr>
<tr>
<td>Being Forgetful, Difficulty Remembering</td>
<td>3.10</td>
<td>2.1</td>
</tr>
<tr>
<td>Irritability</td>
<td>3.05</td>
<td>2.1</td>
</tr>
<tr>
<td>Needing Supervision</td>
<td>2.95</td>
<td>2.5</td>
</tr>
<tr>
<td>Difficulty planning and organizing</td>
<td>2.90</td>
<td>2.1</td>
</tr>
<tr>
<td>Difficulty setting realistic goals</td>
<td>2.90</td>
<td>2.2</td>
</tr>
<tr>
<td>Difficulty bring emotions under control</td>
<td>2.90</td>
<td>2.5</td>
</tr>
<tr>
<td>Temper outbursts</td>
<td>2.85</td>
<td>2.6</td>
</tr>
</tbody>
</table>

*Possible range of scores for scale is 1 to 7

Living and Dealing with the Changed Person

The open-ended questions supported the findings on the PCL-FC, in that many of the caregivers (N=10) reported living and dealing
with the "changed person" as extremely stressful. In particular, family caregivers who were spouses seemed particularly distressed by these changes (N=7). Difficult, aversive and unusual behaviours (ie., dependency, childishness, impatience) were described repeatedly as a source of great stress. Two wives comments illustrate how these changes made it extremely difficult for the caregivers to cope and adapt to the "new person":

I am in a marriage, but not with the person I married. I am married to someone that I don't know. Basically, I am like a single parent with 2 children instead of one. I see bits and pieces of that person, but he doesn't remember what he was like...he had everything going for him...I don't know if he will ever be back to the same person (Case # 19)

His personality is so different now, before his accident he was an extremely meticulous person, everything he did was close to perfection...he was very organized... He is different now...it's like his mind has been mixed up, like a puzzle that has been thrown into a bunch of pieces...he still has the right pieces he just doesn't know where they go...it's like he has misplaced the cover of the puzzle...he doesn't know what the picture should look like (Case # 16).
Another concern was related specifically to head-injured males and aggressive behaviour towards their children (n=5). Comments such as "I'm concerned about his behaviour towards my daughter", "I am concerned about how they will interact together when they get home", "I am not sure what he is capable of with her", typify such concerns. Problematic behaviours observed by caregivers towards their children included: anger, irritability, unpredictability, jealousy, bossiness, strictness, shouting, and rudeness. One wife described how her husband "bullied and belittled" his daughter as follows:

He gets jealous of her and the amount of attention he perceives she gets from me. He will argue repetitively with her over and over again about the same thing... saying things like "Mommy loves me, not you". He doesn't connect that she is only 2 years old...he cannot reason what a child of 2 can and cannot do. He expects her to behave in a certain way and doesn't realize it is because she is so young that she does the things she does...He is constantly disciplining her and yelling at her for no reason (Case # 19).
A few explicitly said they feared that the head-injured person would be physically violent towards their children (n=3). One wife describes her concern:

The head-injury has changed my husband's ability to parent. This is a big problem for me. He is unreasonable when it comes to discipline, he spanks our son beyond the normal strength a father would use. His anger comes out more when our son is around. He needs to be heard and doesn't like to be interrupted or not listened to (Case # 2).

They were even hesitant about leaving their children in the same room with the fathers. In fact, one caregiver's fear of violence was so severe that she had refused to have her child in their home upon her husband's discharge from hospital. She described her concerns:

I wonder when I will be able to blend our son back into our life and home. He is staying with my mother right now...I don't want my husband around him, he is just too unpredictable with him...I am not sure, but I think he could lose it once with him and hurt him badly (Case # 2).

These caregivers were concerned about how these behaviours would affect their children in the long-term. All of these caregivers
expressed a need to learn how to deal with these behaviours to prevent disturbances in the child or alienation of the head-injured person.

All caregivers worried that eventually they would become worn out by the prolonged demands of dealing with difficult and demanding behaviours. Psychological distress was clearly associated with the head-injured person's unusual dependency on the caregiver. A women described concerns about her husband's child-like dependency as follows:

I am concerned about how I will manage with him being home on a 24-hours basis. I have a big problem with the way that he relates to me...it's like 'puppy love'...he thinks I am a 'saint' and always wants to be holding and touching me. He completely invades my personal space. When he comes home on week-end passes, I am always glad to bring him back to the hospital. We [daughter/caregiver] have adapted to life without him, and his personality has made us not adapt to him...It worries me, when he is home permanently and I have no break from him...I think he will demand more attention from me, he is smothering me now, but I think he could suffocate me (Case # 19).
Another caregiver, a mother of a young head-injured woman, describes similar concerns around dependency:

She is dependent on me all the time, even though she doesn't have to, if I encourage her to do things on her own she gets mad at me and that is difficult to handle...When she is home on weekends, I have to get her clothes ready to go out, make her meals and clean up after her. This is a big strain for me I need to be constantly helping her and at her beck and call or she 'freaks out' (Case # 7).

Concern for the head-injured person's safety and emotional well-being as a result of cognitive and behavioral changes were also other sources of stress for some caregivers (n=7). Caregivers feared a reoccurrence of another accident or head-injury and were unsure about the amount of time they could leave the head-injured person unattended. Five caregivers also expressed concern about the emotional well-being of the head-injured person. They anticipated that their relatives would experience loneliness, frustration, poor self-esteem and depression. One caregiver described his concerns for the physical and emotional well-being of his partner:

I don't even know if I will be able to leave him alone all day, it is worshisome. I worry that if he gets too bored
he might wander off and get lost... He can't be out on the streets unsupervised. He can't see correctly plus his memory and judgement are impaired. I am also concerned that with him being alone so much and having so much time to himself to think, he might get severely depressed. He is already severely depressed. I don't know what I can do to prevent this from happening (Case #14).

Additional Responsibilities and Altered Family Roles

The most frequent source of concern expressed by family caregivers related to worry about their ability to cope with all of the demands that would be placed on them. Caregivers who had been able to maintain work, family, and household responsibilities while their relatives were institutionalized faced the need to provide continuous care. Many expressed concern regarding their ability to meet the multitude of needs of the head-injured person as well as maintain their normal activities of daily living. One daughter describes her concerns as follows:

I am concerned about whether or not I will be able to pull it off and whether I will be able to handle it. I will be responsible for all aspects of her care, that is cooking, cleaning, incontinent care, and emotional care... I am
worried about whether I will be able to cope with this on a 24-hour basis. I have heard caregivers get depressed and end up in psychiatric hospital, so I am worried that I could be affected like that (Case # 4).

Similarly, a wife said:

It concerns me that I may not have any time for me. My husband needs a lot of physical care, he needs to be washed, groomed, dressed... My daughter needs a lot of attention and I must work part-time. I have an attendant coming in when I am gone to work because the doctor said he needs constant supervision. But, this is just for when I work, I worry about my fatigue level, will I have the strength to carry out all the demands on my time (Case # 15).

The alteration of family roles and the need to assume new roles contributed to increased stress amongst many of the caregivers (n=8). Most (n=14) described how the sequelae of head-injury had resulted in a marked disruption of normal family roles. Caregivers had assumed the roles of the injured person to compensate for his or her decreased levels of functioning. Common new roles and responsibilities assumed included: participating in rehabilitation therapies, dealing with health care system and
insurance companies, becoming the sole income earner, and
managing finances. A wife explained the effects of these role
already experienced:

My life is upside down, there is a total reversal of roles,
he was the protector and provider and now it is completely
reversed...every person in a relationship has their defined
roles...I have now become the protector and provider for our
family...his personality is so different [now]...(Case # 16).

Another common source of stress pertained to learning the caregiver
role (n=8). The acquisition of the role of caregiver added to the
responsibilities of their previous roles. Most wives (n=5) said
that the role of caregiver is different from the role of wife. The
majority of the caregivers (n=15) felt they were being placed as
the "care provider" without adequate support or knowledge.
Specifically, they felt unprepared to provide various forms of
therapies, emotional support and manage difficult behaviours.

Lack of Information, Professional Support and Community Resources

A lack of specific, tailored information about the head-
injured person's individual needs was repeatedly expressed by
caregivers (n=7). A daughter and wife described their
dissatisfaction with her lack of information as follows:
Caregivers are not educated in terms of what therapies they should be doing. I think the caregivers should be more involved in their care...we should be educated in terms of the therapies...so that they [head-injured persons] can continue getting stimulation at home...they need consistency and structure in their lives...I am fearful that he will regress. We need to be educated regarding how to occupy his time, to not just having him sitting at home all day. Occupational therapy needs to show us how to bathe him, shave him...I don't know if it is safe to shower him or not. The education program for families at the hospital is too generic, they need to tailor their teaching to the patient's specific needs, since not all patients have exact same needs. My father, for instance, is extremely debilitated physically and mentally, we need a lot of training (Case # 10).

I need help in learning my role as a caregiver and how to accomplish this role. This is one of the most common complaints I hear from families and friends of the head-injured. I don't know how to cope with this person; I don't know how I can help (Case # 20).
The three family caregivers whose relatives also had severe physical disabilities were very concerned about learning physical care activities such as incontinence care, lifting, ambulating, preparing meals, feeding, bathing and dressing.

Caregivers tended to be particularly concerned that their lack of preparation would contribute to neurological and physical regression in the head-injured person (n=10). They felt tremendously responsible for the ultimate outcomes of their relative after discharge. As a result, they described wanting to know how to maximise the effectiveness of rehabilitation and prevent the head-injured person from getting worse. One wife describes her concerns as follows:

I want to know what to do. I don't want to do the wrong thing. I am wondering whether we will be able to care for him adequately. I need information about how I can complement professional therapies when he is home (Case #18).

Two caregivers felt ill-equipped to assume responsibility for the management of gastrostomy feedings. As one wife explained:

I am concerned medically about him, what if something happens to him, he is being fed by a g-tube and often has
gastric reflux, what if he was to aspirate? What would I do?...I don't know about g-tubes, like how to care for them or how to recognize signs of problems with it (Case # 15).

Caregivers also found relating to health care professionals as problematic and a source of stress (n=7). In particular, they perceived communication between themselves and health care providers as poor. Some caregivers felt unable to access physicians or nurses for information, others felt they had to "fight" for information and/or do their own research to obtain information (n=3). Some said that the lack of expertise of health care providers added to their own uncertainty (n=3). Several commented that information should be offered by health care providers because the caregiver didn't know what questions to ask (n=6). Finally, three caregivers expressed a need to have their opinions used in planning the head-injured patient's treatment or rehabilitation.

Caregivers (n=7) also identified the lack of professional support available in the community for themselves and the head-injured person as a stressor. Fourteen expressed the need for professional support such as having telephone access to a physicians or other experts at the hospital, therapists with
expertise in head-injury rehabilitation, psychosocial counselling for the patient and family, access to specialized head injury services. Some caregivers had noted that a wider range of post injury services are available if the family has private money or receives money through litigation or insurance. Extra services include: attendant care, vocational training and cognitive rehabilitation. Very few specialized community programs are publicly funded. One caregiver, discouraged with such inequities, explained:

I am very disillusioned and disappointed with the system, there should be financial support for us but there isn't. Because he was assaulted we don't get any money...if he was in a car accident the no fault insurance would have given him a weekly income and paid for his rehabilitation after he leaves the hospital...but because he was not, he is not granted any income on a weekly basis, he just becomes one of the crowd when he leaves the hospital...everything just drops off...we are on our own to fend for ourselves (Case # 16). The three caregivers from smaller communities, felt the services offered were very limited. Their relatives would be part of general rehabilitation programs, rather than specialized programs
for head-injured persons. It is noteworthy that all three of these families were considering moving in order to be closer to more specialized services.

In summary, the quantitative and qualitative findings are remarkably similar related to stressors causing caregiver stress. The symptoms on the PCL-PC supported the theme that emerged from the qualitative data around living and dealing with the changed person. Symptoms such as dependency, impatience, irritability, temper outbursts were associated with high caregiver strain. Further, other symptoms identified by caregivers on PCL-PC, such as needing to be supervised and difficulty planning and organizing, support the qualitative data which indicates that changed roles and increased responsibility for the caregivers were major stressors.

Effects of Stresses on Family Caregivers

Using an open-ended question family caregivers were asked how they thought the head-injury had affected their lives. When necessary, a probe statement was used to elicit the impact it had on their social lives, routine activities and roles, and finances. Not all persons commented on all three areas. In general, the caregiving experience was reported to be associated with negative emotional states, physical health problems, disruptions in social
life, disruptions in family and marital relationships and financial difficulties. Appendix I summarizes the frequencies of the major categories related to effects of stresses on family caregivers.

**Negative Emotional States in the Caregiver**

A negative emotional state was experienced by most family caregivers (n=16). Psychological distress was related to feelings of guilt, anger, isolation, fatigue, hopelessness, and frustration. As one middle-aged immigrant woman stated:

> I feel very alone, I have no support, I am in a strange place, with no family or friends to help me. A head injury is the worst thing that could happen to a family...It has been the worst thing that has ever happened to me in my whole life. The most depressing thing for me is that my future life probably won’t be fulfilling. I won’t have a happy and fulfilling marriage and life (Case # 6).

Eight caregivers (n=8) described themselves as “depressed”, "stressed out", "anxious", "burnt out", or "out of control". A young wife explained:
I feel so out of control with my life. I am going to counselling right now. I can't focus or concentrate on anything, I forget things easily, I forget appointments...you name it...I have no schedule or structure in my own life...

I wonder if I will ever be able to control my life again and be able to make decisions without losing my concentration (#2)

The caregiving experience had generated negative feelings towards the head-injured person for 5 caregivers such as: anger, hostility and resentment. Difficult behaviors were strongly associated with feelings psychological stress in family caregivers.

Physical Health Problems in the Caregiver

Many caregivers complained of general physical problems such as decreased energy (n=5), fatigue and extreme tiredness (n=9), inability to concentrate (n=3), insomnia (n=5), poor appetite (n=3), and stomach cramping and/or nausea (n=3). However, these caregivers tended to minimize or disregard their own symptoms as being unimportant. The reason cited was the necessity for all of their attention to be directed toward their injured relative.

Disruption of the Caregiver’s Social Life

Caregiving demands restricted the ability of virtually all caregivers to pursue work, friendships, sporting activities and
hobbies (N=18). In some instances, the behavioral changes in the
head-injured person had become obstacles to effective social
interaction and relationships with friends (n=6). For example, one
caregiver explained that she had stopped going to "weight watchers"
after her jealous husband continually accused her of having an
affair. Another wife described her husband's difficulties with
socializing:

"...he is resentful of any time that I spend away from him or
that friends take away from him. I tried to have some
friends over one weekend...to see how it would go...but he
just sat there all night with his arms crossed, staring at
me...when he would catch my eye, he would motion with his
head for them to leave...so I know I won't be seeing them
as much in the future. He is very possessive of me and the
time I spend with him" (Case # 19).

Some caregivers reported that their fatigue level left very little
energy for socializing (n=5). Further, embarrassment or fear of
stigma were noted by caregivers as limitations to social
activities. As one wife describes:

I am very concerned about going out in public with him, he is
very 'mouthy' and will tell people off...he also likes children and he will go up to them and tease them, I am very concerned about how people will react to that, especially these days with everyone concerned about men attacking children...every time he eats he 'wolfs' down his food...I will tell him not to do it but he gets upset and frustrated with me (Case # 16).

Feeling trapped in the caregiving situation was common (n=15). Caregivers felt "tied down" when they tried to work full-time or keep a social schedule. In most cases they felt their own interests and needs were submerged by the needs and demands of the patient. Many caregivers said their new role meant that they must plan in detail and not do things on the spur of the moment. Words and phrases such as "real intense", "exhausting", "stressful" and "hectic" were used to describe their anticipated caregiving role as 2 wives described.

I am feeling so bogged down with everything related to him.

I know he's been through so much, but it is difficult to give so much of yourself for someone else. It's almost like nothing else matters in my life. It's almost to the
point that I can't plan or look forward to anything (Case # 2).
I haven't gone anywhere or done anything since the accident 10 months ago. I haven't had a day to myself, I used to go out with 'the girls' regularly ...to gab and talk about our problems. I haven't talked to anyone, particularly about my problems. My needs are the least important. I don't have time to think about myself (Case # 20).

Finally, for caregivers who were immigrants or from another city, the stress of being in an unfamiliar place, coupled with the lack of family and friend support aggravated their sense of loneliness.

Disruption in Family and Marital Relationships

Another pervasive theme was the disruption in family and marital relationships. All of the spouses/partners (N=11) expressed some uncertainty about the future state of their marriage or relationship with a "different person" who had many antisocial and demanding behaviours. They described feelings of "guilt", "obligation", "hope for improvement", "responsibility" and "past gratitude to the spouse" as reasons for remaining in the relationship. For example, one fiancee describes her feelings related to the future of her relationship:
It's has been a very difficult time, there have been times when I have really questioned whether we would stay together, I feel I am obligated to stay with him and I know I would feel guilty if I left him, he relies on me so much (Case # 5).

A wife revealed her feelings of guilt and obligation towards her husband:

If my husband gets better, I mean back to normal, I will divorce him, but if he doesn't I will stay with him. I have been through so much with him in the past, he has not been a good husband to me. He was always irritable and angry at me and the kids and spent very little time with us. My situation is worse than having a dead husband, now the stress is bigger because for the rest of my life I will live with a disabled man. I can't leave him because I know I will always feel guilty. After 17-18 years of marriage you can't leave him and not feel guilty (Case # 6).

Difficult relationships with extended family, particularly "in-laws", added to four caregivers' sense of stress and isolation. These caregivers felt that the manipulative behaviors of the head-injured person contributed to the strain between in-laws as he/she
rarely demonstrated negative behaviors around them. As a result, these spouses felt they were perceived by their extended family as over-exaggerating and being pessimistic about the head-injured person's condition. Spouses received little support, particularly from in-laws and felt they were looked upon with suspicion and mistrust.

**Financial Difficulties**

The majority of caregivers (n=15) reported mild to severe financial problems as a result of the injury (n=15). The problems arose due to several factors including: lost employment, inadequate insurance coverage, house renovations, double mortgage payments, transportation expenses and relocation costs, medication expenses, and cost of childcare, parking and restaurants. A wife whose husband was self-employed describes her financial difficulties as follows:

My biggest stress is my economical situation. I have no job experience and therefore am not desirable to a potential employer plus I have two children and my husband won't be able to work. Most of the insurance covers more physical things like loss of limbs, or blindness, there are no clauses for mental changes from head injury. To sue the
driver and get money you need a good lawyer and that costs money which we don't have" (Case # 16).

**Caregivers' Reports of Uncertainty**

Caregivers' perceptions of the uncertainty related to the head-injured persons' illness were examined by Family-Caregiver Uncertainty in Illness Scale (FCUIS). The internal consistency reliability of the FCUIS, assessed by Cronbach’s alpha, was .83. When the FCUIS was divided into Mishel's four factors, the alpha coefficients of all four factors were less than .70. Since the minimal acceptable limit for the alpha coefficients in a scale is .70 (Nunnally, 1978) only the overall score of the FCUIS was used in further analysis.

The overall scores of the 31-item FCUIS for the 20 caregivers ranged from 52 to 106 (Mean=85.8, SD=14.1). The possible range of scores is 31 to 155. Hence, caregivers felt a moderate amount of uncertainty prior to their relative's discharge from rehabilitation. The frequency distribution of the total FCUIS scores is presented in Appendix J.

The relationship of selected demographic and injury-related factors to uncertainty score was explored. The variables of education and caregiver to patient relationship were dichotomized
into high and low education groups and spouse and child/parent group to facilitate analysis. There were no differences in FCUIS scores on the basis of gender, caregiver relationship to the patient, education of caregiver, or surgery as determined by independent T-tests. Appendix K summarizes the relationship of demographic and injury related data to FCUIS scores.

In order to describe the nature of uncertainty in this particular sample family caregivers were asked to describe the kinds of things that were causing the most uncertainty for them. Categories which emerged were labelled: Uncertainty about the Head-Injured Person’s Immediate and Long Term Recovery, Uncertainty about the Future and Uncertainty about Resources (Financial, Services & Information). Major categories of caregiver reports of uncertainty and their frequencies are seen in Appendix L.

Uncertainty about Immediate and Long Term Recovery

Feelings of uncertainty related to the head-injured person’s eventual limitations were described by all caregivers. The extent of potential permanent cognitive and personality changes was a dominant concern for most caregivers (N=16) and permanent physical disabilities were a concern for 5. One mother described her uncertainty about her daughter’s recovery as:
I am uncertain about whether she truly will achieve a full recovery and whether there will be any long-term mental effects upon her. Her personality is different...I wonder if she will ever be back to the same person. The toughest part is the uncertainty related to recovery.

In a related vein, many caregivers (n=14) expressed uncertainty about what the future would hold for their relatives. Specifically, caregivers were uncertain about how much improvement realistically could be expected. Caregivers wondered whether the head-injured person would return to work (n=5) or school (n=4), be able to fulfil previous roles (n=3), achieve set goals (n=3), or ever be the "same person" again (n=10). As one wife explained:

...there is uncertainty about what he is going to be like in a year, will he be able to work? Will he continue with his art and his studies? Depending on if he will be able to function like a normal person, we wanted children, now I wonder if he will be able to care for them? I also wonder whether he will regain his personality, he is like a child of 5 or 6, I am not sure if he will change, is he going to be the same person I fell in love with? Is he going to be the same person I married? (Case # 16).
Some caregivers spoke about the probable permanent limitations of the head-injured person (n=7), while others seemed to envisage full recovery and were merely anxious about the length of time which would pass before recovery would be complete (n=3).

Uncertainty about the future of the family and the caregiver was also commonly expressed (n=12). The uncertain nature of the patient's recovery made it particularly difficult for caregivers to plan for their own futures (n=10). Not knowing whether caregiving would be a few months or extend over several years was particularly perplexing. Many caregivers felt unsure about what caregiving would mean to the family, in a practical sense, on a day to day basis (n=6). They were unable to anticipate the time and efforts required for providing care after hospital discharge. As one daughter explained:

His diagnosis left a lot of questions unanswered, how well he would do, if he would get better, if he was ever going to be able to come close to the person he was, what the future holds for the family in order to deal with the injury, that is to help him in his recovery and make him comfortable, what this would mean for the family (Case # 10).

One father described his uncertainty:
I am uncertain how everything will settle out. The living arrangements, the care involved, you name it...just how we will deal with this 7 days/week...everyone works...how the scheduling will all work out...you know, the mechanics of living...just how it will all fit into everyone's lives (Case #18).

Uncertainty about Resources

The long-term financial implications associated with the head-injury were a common source of uncertainty for the majority of the caregivers (n=18). Further, this financial uncertainty created uncertainty about services available to the head-injured person upon discharge. Factors contributing to the uncertainties were the unknown costs of the rehabilitative services and attendant care, lack of knowledge about how to deal with insurance companies, lawyers, the "red tape" that was associated with accessing money, and the ability of the head-injured person to return to the workforce.

Living "one day at a time" became an anchor in the lives of some caregivers as they struggled with an uncertain future. One wife poignantly described her uncertainty as:
This (head injury) is a big disaster in the family, but in my situation the disaster is bigger because I am an immigrant. I have no job, no house and I have 2 children who want and need to be educated...and now with this injury it is much worse because my husband is not working. I am extremely uncertain about what will happen to my family...We might be able to get some money from an insurance agency, but they have all kinds of lawyers who probably are better than the ones that I could afford and so it won't be much that we will get. I may have to get a full-time job, but will I find one at my age, I am 42 years of age, who will hire me? (Case # 5).

Uncertainty also arose due to caregivers’ perceptions that they had insufficient information about head-injury recovery (n=10). They felt they had received insufficient information regarding the head-injured person’s treatments, prognosis and anticipated difficulties. Several caregivers wanted to know more details regarding the nature and extent of the head-injured person's limitations (n=8). In particular, caregivers expressed a need for complete information on the patient's physical problems such as weakness, headaches, dizziness; and mental problems such as confusion, memory, communication (n=7). Knowing the stages that
the head-injured person would go through during recovery was important to some caregivers (n=3). Several caregivers would have also liked information regularly on the patient's rehabilitative or educational progress (n=4). Five caregivers viewed their knowledge of the social services as inadequate and wanted more information on available services.

**Perceived Information Needs as Measured by the CINO**

Caregivers' perceived information needs related to the management of their head-injured relatives' care at discharge was measured by the CINO. The internal consistency reliability assessed by Cronbach's alpha was adequate for the total scale (.93) and five of the six subscales (see Table 6). The Activity of Daily Living subscale alpha coefficient of .69 was inadequate (Nunnally, 1978). Caregivers perceived a moderate amount of discharge information to be important in the management of their relative's care at home. Scores on the total CINO ranged from 80 to 228, where 250 was the highest possible score and 50 was the lowest (Mean=154.25, SD=33.4). Frequency distributions of the scores is seen in Appendix M. Table 6 outlines total scale and subscale scores and measures of central tendency.
Table 6.

CINO: Measures of Central Tendency and Dispersion and Internal Consistency Reliability Coefficients

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Mean</th>
<th>SD</th>
<th>Range</th>
<th>Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medications</td>
<td>14</td>
<td>6</td>
<td>5-25</td>
<td>.82</td>
</tr>
<tr>
<td>(25)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Activities of Living</td>
<td>31</td>
<td>9</td>
<td>19-55</td>
<td>.69</td>
</tr>
<tr>
<td>(65)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community &amp; Follow-up</td>
<td>30</td>
<td>7</td>
<td>18-41</td>
<td>.71</td>
</tr>
<tr>
<td>(45)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feelings related to condition</td>
<td>13</td>
<td>5</td>
<td>4-20</td>
<td>.74</td>
</tr>
<tr>
<td>(20)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quality of Life/Symptom mgt.</td>
<td>36</td>
<td>9</td>
<td>14-47</td>
<td>.85</td>
</tr>
<tr>
<td>(50)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatment and Complication</td>
<td>31</td>
<td>9</td>
<td>9-44</td>
<td>.85</td>
</tr>
<tr>
<td>(45)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TOTAL CINO</td>
<td>154</td>
<td>33</td>
<td>80-228</td>
<td>.93</td>
</tr>
<tr>
<td>(250)</td>
<td></td>
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To identify which categories of information were perceived as being the most important, the mean subscale scores of the CINO were examined. Since the CINO subscales were composed of an unequal
number of questions, percentage means were calculated (See Table 7).

Table 7.

Categories of Information Perceived as Being the Most Important and Percentage Mean Scores

<table>
<thead>
<tr>
<th>Subscale</th>
<th>no. of items</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enhancing Quality of Life/Symptom Management</td>
<td>10</td>
<td>35.9</td>
</tr>
<tr>
<td>Treatment &amp; Complication</td>
<td>9</td>
<td>30.9</td>
</tr>
<tr>
<td>Community and Follow-up</td>
<td>9</td>
<td>29.5</td>
</tr>
<tr>
<td>Feelings about Condition</td>
<td>4</td>
<td>12.7</td>
</tr>
<tr>
<td>Medications</td>
<td>5</td>
<td>13.9</td>
</tr>
<tr>
<td>Activities of Living</td>
<td>13</td>
<td>30.7</td>
</tr>
</tbody>
</table>

Specific information perceived as important by caregivers was identified by listing the ten items on the CINQ with the highest mean scores (See Table 8). Table 9 lists additional types of information, not mentioned in the CINQ scale, that caregivers felt was important to know prior to discharge. The t-test for independent samples were used to determine if there were any differences between the CINQ scores and any of the demographic
Table 8.

**Most Important Information Items on CINO with Highest and Mean Score Prior to Discharge From Rehabilitation**

In order to manage my relative's care at home I need to know:  

<p>| | | |</p>
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<thead>
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<tbody>
<tr>
<td><strong>1.</strong> How to recognize if the head injury is getting worse.</td>
<td>4.40</td>
<td>1.1</td>
</tr>
<tr>
<td><strong>2.</strong> How this injury will affect my relative's future.</td>
<td>4.35</td>
<td>1.2</td>
</tr>
<tr>
<td><strong>3.</strong> What complications might occur from my relative's injury.</td>
<td>4.35</td>
<td>1.2</td>
</tr>
<tr>
<td><strong>4.</strong> What resources are available in the community to help my relative.</td>
<td>4.10</td>
<td>1.2</td>
</tr>
<tr>
<td><strong>5.</strong> What resources are available in the community for myself or my family.</td>
<td>4.05</td>
<td>1.3</td>
</tr>
<tr>
<td><strong>6.</strong> Which complications I should seek immediate help for.</td>
<td>4.05</td>
<td>1.3</td>
</tr>
<tr>
<td><strong>7.</strong> What symptoms will get worse and what symptoms will improve or stay the same.</td>
<td>3.95</td>
<td>1.4</td>
</tr>
<tr>
<td><strong>8.</strong> How long my relative will need to be cared for.</td>
<td>3.95</td>
<td>1.3</td>
</tr>
<tr>
<td><strong>9.</strong> How to recognize signs and symptoms of a seizure.</td>
<td>3.85</td>
<td>1.7</td>
</tr>
<tr>
<td><strong>10.</strong> When my relative can start to do regular activities safely.</td>
<td>3.85</td>
<td>1.4</td>
</tr>
</tbody>
</table>

*Possible range 1 to 5*
Table 9.

Additional Items of Information Identified by Caregivers as Important in the Management their Relative's Care.

In order to manage my relative's care at home
I need to know:

1. How to deal with my relative's negative behaviours towards the children.
2. What to do when my relative is upset or acting strange.
3. Why my relative acts in ways that are different, difficult or strange.
5. What the different out-patient rehabilitation programs provide.
6. Where my relative can go to talk with people who have had a head-injury with similar levels of dysfunction.
7. How to help my child deal with the changes in my spouse.
8. When my relative can return to school or work.
9. What I can do to help my relative with therapy (speech, occupational, physical) in order compliment professional therapy.
10. How to deal with my relative's behavior changes (ie., repetitive complaints, dependency)

Data (see Appendix N). There was no statistically significant differences in overall mean scores on the basis of the sex of
caregiver or patient, relationship to patient, education level of caregiver, or whether the patient had undergone surgery. Pearson's R Correlation was used to determine if there was any relationship between injury related data, age and CINQ scores. The results indicated that age was not related to perceived information needs. There was however, a significant positive correlation between clinical indicators of severity of brain injury (length of stay, PTA) and family caregivers' information needs.

In summary, regardless of the question being explored, the quantitative and qualitative analysis both highlighted concerns related to the same phenomena, namely family caregivers' concerns regarding living and dealing with the changed person; immediate and long-term concerns related to their role; and effect of stresses related to the head injury on their lives. In the next section, the findings will be discussed and considered in relation to the theoretical underpinnings of Lazarus and Folkman (1984) and Mishel's Theory of Uncertainty (1988) and the related research literature.
CHAPTER FOUR

Discussion of Findings

This study was undertaken to explore the stress, uncertainty and information needs of family caregivers of head-injured adults at the time of discharge from rehabilitation settings. Twenty family caregivers, 15 women and 5 men, were interviewed within 7 days of their relative's discharge. Similar to samples in other studies, most of the head-injured people in this study were male (n=12), with a mean age of 39.5 years (SD=16.8). Most had sustained severe head injuries through motor vehicle accidents (Cooper, Tabaddor, Hauser, Shulman, Feiner, & Factor, 1983; Jacobs, 1988; Livingston et al., 1985; Schwartz, Sharkey & Andersen, 1991; Snow, Macartney-Filgate, Schwartz, Klonoff, Ridgley, 1988). In contrast to findings from some American studies, only 1 injury was the result of violence (Cooper et al., 1983). Reflecting the fact that many head-injured patients have multiple injuries (Snow et al., 1988) almost half of this sample had at least one body system other than the central nervous system involved. While some of these injuries were minor, others included an amputated arm, loss of an eye and severe orthopaedic injuries.
Several researchers have suggested that head-injured persons do not represent a random sample of the population. They are more likely to have exhibited social adjustment problems, including violent behaviour, substance abuse, and poor school performance. (Fahy, Irving & Millac, 1967; Oddy et al., 1978; Hall, Karzmark, Stevens, Englander, O’Hare, Wright, 1994; Hass, Cope, & Karyl, 1987; Jacobs, 1988). Alcohol is a strong predisposing factor in traumatic head injury (Snow et al., 1988) and elevated blood alcohol and/or cannabis levels have been found in more than 60% of the subjects (Soderstrom, Trifillis, Belavadi, & Shankar, 1988; Soderstrom & Cowley, 1987). In the present study, three patients had consumed alcohol prior to their injuries and five others were strongly suspected of having done so. Thus, there may have been strains and difficulties within these families prior to the head-injury which could be responsible for family anomie following head injury (Gleckman & Brill, 1995).

Consistent with other studies of family caregivers for head injured persons (Kreutzer et al., 1992; Acorn, 1993) 80% of the caregivers in the present study were female. The high incidence of female caregivers is reflective of the fact that proportionately more males than females sustain head-injuries (Snow et al., 1988;
Cooper et al, 1983) and supports cultural ideologies about caregiving as a traditional and accepted role for women (Thurer, 1983). An interesting finding was the change in marital status of caregivers after the head-injury. Two caregivers, previously separated from their husbands, reunited with their spouses and one caregiver had moved in with her head-injured boyfriend. Reasons for the change were "obligation" to their spouse and "convenience" for caregiving. Spouses' feelings of responsibility and gratitude for head-injured person coupled with guilt and fears of social rejection may make it difficult to turn away from a caregiving situation (Lezak, 1988). Most caregivers were employed or homemakers full-time. The majority (75%) had more than 12 years education which contrasts to the 75% noted in the Ontario Head Injury Association Statistics who had 12 years education or less (Ontario Head Injury Association, 1991).

**Living and Dealing with the Change Person**

The behavioral and characterological alterations in the head-injured person were a major source of stress for caregivers. These changes included increased dependency on others, impatience, poor memory, irritability and fatiguing quickly. As researchers who focused on later phases of the head-injury trajectory have found
the mental and behavioral changes were much more related to caregiver distress and burden by family caregivers than physical and speech-language changes (McKinlay et al., 1981; Oddy et al., 1978). Many researchers have indicated that these deficits are known to be the greatest obstacles to family and community reintegration (McKinlay et al., 1981; Ben-Yishay & Diller, 1981; Oddy & Humphrey, 1980). Although the study period was different, these results confirm previous research which suggests an association between cognitive and behavioural deficits of head injured persons and complaints of burden and psychosocial distress in family caregivers (Brooks & McKinlay, 1983; McKinlay et al., 1981; Thomsen, 1974; Mauss-Clum & Ryan, 1981; Livingston et al., 1985).

The present study provided insight into the specific impact of living with a changed person. Caregivers depicted the terrific burden that resulted from the unusual dependency of the head-injured person. Child-like behaviors, being excessively demanding, and needing continual supervision created great distress. Previously, Lezak (1988) observed that families seem to accommodate or compensate for mild personality changes but concluded that families suffer when faced with caring for a head-injured
individual who is "dependent, demanding, irresponsible, ill-mannered, or frankly dangerous" (Lezak, 1978, p. 593). Lezak also noted that the most severely injured persons related to their caregivers much as young children do to their mothers.

Unfortunately, these psychological changes do not seem to abate with time. Follow-up studies years after the injury demonstrate continuing similar behavioural and psychological problems (Thomsen, 1984).

In addition to the child-like dependency, many head-injured persons displayed aggressive behaviour towards children (n=5). Caregivers who were mothers feared that their young children were especially vulnerable to the emotional and behavioral difficulties of their head injured fathers. They described how the children had become targets for the head-injured person's frustrations and anger. Children also unknowingly became competitors with their fathers for the caregiver's attention. Some caregivers feared that the head-injured person would actually become physically violent towards their children. Rosenbaum and Najenson (1976) and Lezak (1978) reported a decrease in the head injured person's role in parenting and increased resentment towards children. Urbach and Culbert (1991) in a case review article looking at head-injured
parents and their children, indicated that the "changed" head-
injured parent may predispose the child to many problems such as:
attachment difficulties, cognitive and social developmental delays,
and impaired self-esteem.

The potential that their children would suffer was a major
source of stress for the caregivers who were mothers in this study.
There maybe constant anxiety on the part of the caregivers, as they
try to avoid provoking aggressive outbursts and live in fear of
more insults (Brook et al., 1986; Thomsen, 1974; Lezak, 1978).
Caregivers often have to choose between their husbands and children
(Lezak, 1988). As a result, wives face either a severe moral
problem of abandoning the person with head injury or passively
neglecting and abandoning the children. Generally, there is a
paucity of research on the incidence of violence and aggressiveness
towards children and it is unknown whether head-injured females
pose the same threat of violence towards their children.

A related finding of this study was that it provided a glimpse
at the meaning of caring for persons whose behavior had become
profoundly different. The emotional plight of many caregivers was
poignantly revealed in comments about the patient no longer being
the person they married or being a totally different person.
Family caregivers could not, and often did not want to adapt to the negative changes in the head-injured person and felt as if they had essentially lost a family member. Caregivers' difficulties in adjusting to the personality changes in the head-injured person are congruent with other studies findings in this population (Oddy et al., 1978; Lezak 1978, 1988; Thomsen, 1974; Panting & Merry, 1972; Mauss-Clum & Ryan, 1978; McKinlay et al., 1981).

The caregivers' responses to these changes in the head-injured may be explicated by Lazarus and Folkman's Theory of Stress and Coping (1984). They postulate that potentially stressful situations are evaluated repeatedly in terms of their significance to well-being and that these evaluations guide coping responses. Stressful appraisals are characterized as involving harm or loss, threat or the potential for harm, and challenge and these three stressful appraisals are not necessarily mutually exclusive. In an multifaceted situation such as family caregiving of the head-injured these might be expected to occur simultaneously (Oberst, Gass, & Ward, 1989).

Appraisal involves the assessment of both the nature of the stressor itself such as high dependency needs and violent and aggressive behaviour and the caregivers resources for coping. The
dramatic transformation of a relationship may itself be a major loss and therefore stressful to caregivers. Another related stressor, high dependency poses a physical and psychological threat to the well-being of the caregiver. Further, the constant level of vigilance that must be maintained to ensure that the patient harms neither himself nor others constitutes another formidable stressor for caregivers. Moreover, most caregivers perceived they lacked the resources and skills to cope with such behavior. It would also seem that families with premorbid histories of alcoholism and other social problems may be at particularly high risk for difficulties as they often lack the resources to cope with such severe stressors (Gleckman & Brill, 1995).

Caregivers have previously reported that they possessed inadequate information related to the management of these personality and behavioral changes (Campbell, 1988) and caregivers in the present study specifically reported that discharge information about enhancing quality of life and symptom management were important to know about. In addition, caregivers specifically expressed a need to develop behavioural strategies to effectively handle disruptions in behavior; appropriate ways to structure living environments and daily activities; how to deal with negative
behaviors towards children; and how to help children deal emotionally with the changes in the head-injured person.

Immediate and Long-term Concerns related to the Caregiver Role

Most caregivers were concerned about their ability to cope with all of the demands in their new roles. Caregivers who had been able to maintain work, family, and household responsibilities while the head-injured person was in hospital faced providing daily care. Caregivers felt an enormous sense of responsibility in relation to the head-injured person’s eventual outcomes but were already reporting that they were fatigued and "burnt out". They were also concerned about the long-term effects of these demands on the family and themselves.

Lazarus and Folkman (1984) believe that novel and complex situations are likely to be appraised as stressful as they can be seen as creating demands that often exceed the person’s resources. Most caregivers who had been interviewed were already bearing new responsibilities and roles. They were in fact, entering the next phase of a new situation already exhausted and emotionally stressed. Lazarus and Folkman (1984) suggest that such enduring or chronic stressors contribute to stress appraisals of harm, threat or loss and can over time wear a person down psychologically and
physically. The harm/loss occurs because of the potential for this to affect the future of the caregiver and the head-injured person.

Uncertainty contributes to the appraisal of a situation as stressful. In illness related experiences, uncertainty intensifies the stressfulness of the situation because the individual is unable to accurately predict its impact or determine what can be done to cope with it (Lazarus & Folkman, 1984). Family caregivers felt a moderate amount of uncertainty related to their relative's condition prior to hospital discharge. Similar levels were reported by family caregivers of brain-injured patients in the acute phase of hospitalization (MacDonald, 1992). The caregivers in the present study had moderate scores on the FCUIS and expressed uncertainty about the nature of head-injured persons' injuries and eventual limitations. Uncertainty also existed about the complexity of treatments and care after discharge; the unpredictability of the long-term financial implications and the ambiguity related to the future effects on the life of the caregiver and the family.

Most family caregivers found themselves in the role of care provider without adequate support or knowledge. Most felt
unprepared to provide the various forms of therapies, emotional support and management of difficult behaviours that would be required. As one wife had explained, I don't know how to cope with this person; I don't know how I can help. Lazarus and Folkman suggests that when faced with a threatening event, individuals will seek information to enable them to objectively interpret the event when it occurs and institute effective coping behaviors (Galloway & Graydon, 1996).

The moderate to high information needs expressed by caregivers at discharge, is compatible with the theory that information needs are identified in order to manage perceived stressors. Prior to discharge, family caregivers expressed a variety of learning needs related to their head injured relative's care at home, including information about: symptom management; physical care, recognition of complications; community resources for the head-injured person and the family; how to boost the head-injured person's self-esteem; how to complement professional therapy's and how to help children cope with the changes in the head-injured person.

Perceived inadequacy of information has been noted to increase stress in caregivers of the head-injured in other studies (Mauss-Clum & Ryan, 1981; Campbell, 1988; Oddy et al., 1978).
Caregivers in this study repeatedly reported that inadequate information was a prime contributor to their stress. The information they had received was considered too generic and was not tailored to the specific needs of their relative. Caregivers were particularly concerned that their lack of preparation would contribute to the neurological and physical regression of the head-injured patient.

Impact of Stresses on the Caregiver

Despite the widespread assumptions that the family is the ideal location for caring and therapeutic activities, the findings emphasized the stressful nature of the caregiving experience. Lazarus and Folkman (1984) indicate that regardless of how an event is defined or conceptualized, a prime importance of appraisal is the effect on adaptational outcomes such as, physical, mental and social health. In short, quality of life and the caregivers' mental and physical health are partly dependant on their appraisal of stressful events.

Mental and Physical Health

The stressful nature of the caregiving experience and the psychological and physical health problems of the caregiver was clearly explicated. Theoretically, Lazarus and Folkman (1984)
indicate that emotional states of all kinds and intensities accompany any appraisal in new situations. Furthermore, they believe that physical illnesses are particularly associated with strong, negative emotions such as anger and fear. Diminished psychological health of the caregiver is a persistent finding in the head-injury literature (Livingston et al., 1985; Mauss-Clum & Ryan, 1978; Oddy et al., 1978; Panting & Merry, 1972; Rosenbaum and Najenson, 1976) and was very apparent in the present study. Predominant negative emotions that caregivers experienced included guilt, anger, sadness, depression, hopelessness, anxiety and frustration. These negative emotions were linked to the head-injured person's changed personality and behavioral disturbances, high dependency needs, the caregivers' social isolation, financial worry, and lack of information. The tremendous responsibility they felt for the head-injured person's eventual recovery was an added source of stress.

For some, the caregiving experience engendered negative feelings such as anger, hostility, resentment and entrapment towards their head-injured relative. In particular, they resented the added physical, household and financial responsibilities, irritating behaviors and being tied down. A few caregivers were
also angry with the head-injured patient for being so irresponsible and thus putting them in this situation. This finding concurs with those of other researchers such as Gans (1983) who found that family members were apt to hate the head-injured person when the disability had resulted from self-neglect or self-indulgence.

In the present study, all subjects voiced intense concern or "commitment" for the head injured person. They expressed feelings of obligation and loyalty as the motivational factors. Commitments do strongly influence the appraisal process by guiding the person into and/or away from situations that can challenge, threaten or harm them (Lazarus & Folkman, 1984, p.57). Many of the caregivers' comments stating fears and worries about the future of the head-injured patient and the concern that he/she would re-injure himself/herself or regress neurologically reflect this commitment.

The impact of caregiving on physical health was also noted by family caregivers. Many complained of general physical problems such as decreased energy, fatigue, and extreme tiredness, inability to concentrate, insomnia, and gastrointestinal symptoms. Although there is substantial evidence in the general caregiving literature to support the fact that the experience can be detrimental to
caregiver's health (Baumgarten, 1989; Goodman, 1986, Guberman, 1990). Until now, only one study examined the relationship between caregiving and ill health in the caregivers of the head-injury (Oddy et al., 1978). Information about changes in caregiver health over time or the incidence of caregiver injuries associated with caregiving are completely missing from the head-injury literature.

Effects on Social Roles and Functioning

Changed Roles

Most caregivers indicated that the sequelae of head-injury had resulted in marked disruption of normal family roles. Most had taken on numerous roles and responsibilities to compensate for the head-injured person's decreased level of functioning. The issue of role changes within families, and the consequent effect on caregiver distress has been a frequent theme in the literature (Acorn & Roberts, 1992; Jacobs, 1988; Mauss-Clum & Ryan, 1981; Rosenbaum & Najenson, 1976; Kozloff, 1987). Researchers (Kozloff, 1987; Jacobs, 1988) documented that family members often assume additional roles and responsibilities to compensate for the increased dependence of the injured person and decreased contact and support from those outside the family. Furthermore, depression levels amongst wives of head-injured men have been strongly
associated with altered family roles and increased responsibility for household tasks and activities (Rosenbaum & Najenson, 1976).

Social Networks and Support

Even prior to discharge providing care to head-injured relatives had had a disruptive impact on family life and the family caregivers' social functioning. The injured person's physical and emotional demands limited caregivers' ability to socialize and participate in recreational activities or pursue interests. In many cases, the inappropriate behaviours of the head-injured person curtailed social outings due to fear of stigma or embarrassment. These problems have also been reported by others (Jacobs, 1988; Oddy et al., 1978; Panting & Merry, 1970; McKinlay et al., 1981; Pearl, 1989; Lezak, 1978; 1988; Mauss-Clum & Ryan, 1981). Feeling trapped in the caregiving situation was a common phenomenon adding to caregivers' sense of isolation.

Social support is one important resource that may be available to caregivers as they appraise their situation (Lazarus & Folkman, 1984, p. 243) and without adequate social support, the caregiver may become ill or the head-injured person re-institutionalized (Lezak, 1988). By definition, social support means having people from whom one receives emotional, information and/or tangible
support (Lazarus & Folkman, 1984, p. 164). In this light, many family caregivers confirmed that lack of social support was a source of difficulty adding to their feelings of loneliness and stress. Further, stress was anticipated to increase after discharge as caregivers perceived a lack of professional support in the community. Caregivers from rural areas felt particularly vulnerable because of the lack of specialized services available.

As in other studies (Campbell, 1988; Mauss-Clum & Ryan, 1981; Jacobs, 1987; Hall et al., 1994; Willer et al., 1994) most caregivers reported mild to severe financial problems and discussed problems of accessing needed services if they did not have private money or legal support. Some families experienced extensive financial distress because they had no insurance coverage, limited coverage because of the cause of the injury, or a gap in their policy coverage. The option of hiring a lawyer and suing for personal damages was often considered an unreasonable risk to take due to already limited resources. These findings become particularly important when taken in conjunction with the predominantly low economic status among families reported by the Ontario Head Injury Association (1991). Further studies are needed to quantify the financial costs to caregivers and their families.
Changed Relationships

Many of the head injured in this study were husbands and the injuries had disrupted marital relationships. Many spouses felt uncertain about the future state of the marriage because their partners had become strangers to them. Lezak (1988) described spouses of the head-injured as being in limbo because they could not get divorced with a clear conscience. She describes gratitude, fond memories, feelings of responsibility, guilt and fear of social condemnation as reason for being reluctant to divorce. Jacobs (1988) noted marital separation and divorce are higher among family members of individuals after head-injuries, when compared to the general population, particularly after the first year post injury. It is noteworthy, that this is the time when most formal rehabilitation services end and the caregiver is faced with the stress of living with the head-injured person with little outside assistance.

Caregivers also felt dissatisfied in their relationships and communications with health care professionals. They were frustrated at being excluded from the rehabilitation plan and found it difficult to gather important information about their relatives' situation. Many felt they had to "fight for" information and
needed to become assertive in order to obtain necessary information. In addition, many caregivers felt misinformed and perceived a lack of professional expertise related to head-injury rehabilitation. Other researchers (Acorn, 1993; Baker, 1990; MacDonald, 1992; Oddy et al., 1978; Willer, Allen & Ferry, 1990), have also identified that caregivers of the head-injured perceive communication difficulties with health care professionals. These findings suggest the need for an approach to rehabilitation which empowers caregivers and offers strong emotional and information support throughout the process.

In this study, caregivers' perception of a lack of information may have been exacerbated by their negative emotional states. Lazarus and Folkman (1984) state that information processing is disrupted when the threat is severe. A heightened state of stress can impede mental functioning and thereby decrease retention of information and individual learning abilities. Thus, family members may not have been able to retain all of the information that had been provided by health care professionals.
CHAPTER FIVE

Summary, Implications and Conclusions

Most research about family caregivers of the head-injured has been conducted during the acute hospitalization period or months after the injury. The present study is the first investigation that explored caregivers' experiences of stress, uncertainty and information needs before discharge from rehabilitation settings. A convenience sample of 20 family caregivers, 15 women and 5 men, took part in this descriptive study. The Theory of Stress and Coping by Lazarus and Folkman (1984) and the Theory of Uncertainty in Illness (Mishel, 1988) were used to conceptualise the study. Subjects completed the Family Caregiver Uncertainty in Illness Scale (FCUIS); Caregiver Information Needs Questionnaire (CINQ); and the Problem Checklist-for Family Caregivers (PCL-FC). They also responded to open ended questions related to their concerns about discharge, sources of uncertainty and the overall impact the head-injury had had on their lives.

The analysis of the quantitative and qualitative data highlighted that family caregiver distress is related to three major areas: living and dealing with the changed person; immediate
and long-term concerns related to the caregiving role; and the
effect of stresses on the caregiver.

This study provides considerable evidence that even before
head-injured persons are discharged home from rehabilitation
settings the caregiving experience is highly stressful. Caregivers
reported significant disruption in their psychological and physical
health, marital relationships, and social life. Dissatisfaction
with their relationship with health care providers was also
expressed. Further, many caregivers reported significant financial
difficulties and anticipated reduced access to needed head-injury
services upon discharge.

Most caregivers in this and in other studies reported that
the physical changes in the head-injured person are less burdensome
than behavioural and personality changes. In particular,
caregivers found living and dealing with "changed" persons who had
become antisocial and aggressive particularly difficult. Wives
reported that their head-injured husbands had become aggressive
with their young children and feared the occurrence of a violent
incident upon discharge. Other sources of stress related to their
ability to learn the caregiver role and anticipated problems with
coping with the multiple demands of the role.
Uncertainty, as measured by the FCUIS were moderate and arose from numerous areas such as uncertainties about recovery and long-term financial concerns. Using the CINQ, family caregivers identified a need for discharge information related to management of difficult behaviours; quality of their lives; the sequelae of brain injury information and community resources as important. This study re-emphasised the need for family caregivers to obtain education and counselling (Grinspun, 1991; Oddy et al., 1978; Panting & Merry, 1972).

These findings extend knowledge of the experiences of family caregivers with a head-injured relative to the immediate discharge period. The catastrophic nature of the injury and the consequent psychological distress have serious ramifications for family caregivers' health and quality of life. Although there are many aspects about the head injury that cannot be changed, some immediate needs can be addressed to make the experience a little less disturbing. Less stress may be felt by family caregivers with adequate resources and support during rehabilitation and at the time of transition home.
Limitations

Although the use of a small convenience sample reduces the generalizability of the findings, their congruence with the findings of other research increases their credibility. The PCL-PC is a newly developed instrument with incomplete reliability and validity testing hence, some caution must be taken when interpreting these results. In addition, extraneous variables such as pre-morbid difficulties in marital relationships, financial problems and behavioral problems were not controlled for.

Implications

Practice

It is clear from this study, that extremely distressing sequelae for family caregivers following a head injury include the cognitive deficits and behavioral changes. However, despite recent advances in rehabilitation techniques and the fact that psychological deficits are the major source of morbidity in this population, few programs have a strong focus on cognitive remediation and behavioral management. The need for such a concentrated program has been stressed in the literature (Grinspun, 1987). Further, family caregivers also need to be considered as crucial members of the rehabilitation team in order to learn
effective intervention strategies to deal with excessive passivity and/or aggression. Because of the potential for violence and family disruption post discharge, priority should be given to developing intervention techniques (i.e., pharmacological, behavioral) to modify the expression of behavioral dysfunction in the head-injured and to assess the potential for violence predischarge.

The findings suggest that health professionals need to be more aware of the difficulties family caregivers experience so that other stresses can be identified and potentially ameliorated. Nurses who spend time with caregivers listening to their point of view may more effectively represent the caregiver's perspective to the health care team. Further they will better equipped to design interventions that are family centered thereby improving the quality of support provided. In doing this, nurses may help caregivers to feel cared for and more satisfied with their relationships with health care professionals.

The disruption in family caregivers' psychological and physical health should also be addressed. Nurses need to be aware of the effects of the many stressors on the caregiver and include these areas in all assessments. This assessment could be enhanced
by developing clinical tools that measure family stress, thereby facilitating the identification of caregivers who are at higher risk for coping difficulties. Such data would indicate where more immediate interventions and resources are needed.

Other methods to help alleviate family stress include structured family meetings with the health care team throughout hospitalization to provide information and support. The meetings might focus on helping caregivers to understand the nature and extent of the head-injured person's limitations and provide a forum to address their concerns and questions. Meetings could occur either collaboratively or with individual team members depending on the situation. Further, nurses could be instrumental in helping family members to create strategies in order to ensure that caregivers maintain a healthy balance between meeting their own needs and those of the patient. For example, by helping families to realize that the rehabilitation process takes months rather than days, nurses could help families to feel comfortable taking time to nurture their own needs and help them lobby for resources and services.

To improve the relationship between the health care professionals and family caregivers, health care providers need to
provide accurate information in response to family caregivers’ queries. Ongoing education for health professionals about head injury sequelae and management is necessary so the information given is congruent with events which will occur. Increased efforts should also be made to integrate caregivers into activities and therapies. This would be particularly constructive in the rehabilitation setting to help family caregivers prepare for the home situation. When family members are included as active “therapists” they can often channel feelings of helplessness and anger into productive involvement in the head-injured person’s recovery (Complair, Kreutzer, and Doherty, 1990).

There exists a need for a more pronounced and better defined nursing role to support and address the complex psychosocial and physical needs of family caregivers. The clinical nurse specialist (CNS) role is capable of meeting many of these needs and may provide continuity and comfort for all families. The implementation of such a role may perhaps improve the relationships between health care professionals and caregivers as the CNS would be familiar to the family and available to address their complex concerns and needs.
Results of this study indicate that family caregivers express many information needs. Therefore before the head injured patient is returned home, information must be made available to all family caregivers to help them prepare for their new role. Almost all family caregivers reported that they had received less information than desired. Since many of the family caregivers did not even know what questions to ask, nurses may need to be the initiator of information. Information needs assessment tools like the CINQ might be useful to determine individualized discharge information needs of caregivers. Because information provided during stressful times is only partially absorbed, it is recommended that information given is on-going and repeated. The consistent and repetitive supply of information is crucial in assisting families to process information and more effectively deal with this devastating experience. Written material and videotapes on the management of symptoms and community and financial resources could serve as adjuncts to nurses verbal explanations.

Community or hospital-based educational support groups could be established to provide an ongoing support for caregivers. Such groups might bring together families to share common problems, discuss difficulties, and provide a non-threatening opportunity to
network with other caregivers. An educational component could be included to help families understand the nature and extent of the head-injured person’s deficits, the management of difficult behaviours, possible coping mechanisms and available community resources. In addition to support groups, telephone access to healthcare providers could be provided by a “hot line” for family caregivers to gain information to questions and concerns.

**Nursing Education**

Information giving will be most effective when delivered by competent nurses who can impart accurate information tailored to the needs of individual family members. In this investigator’s experience, nurses often have limited knowledge related to head injury recovery and the difficulties caregivers encounter which hinders nurses’ ability to assist caregivers in preparing for their responsibilities. This gap in knowledge about head injury recovery was noted by family caregivers in this study. It is important that nurses acquire and maintain accurate knowledge sufficient to support families in this setting. They would also benefit from knowledge and skills related to family nursing theory and family intervention techniques.
Policy

At present, many community care policies are not in synchrony with the realities that caregivers and their families experience. It is clearly evident from the research reviewed and the current findings that family caregivers pay a high price in terms of the impact on their psychological and physical health, the effects on their family and social life, and finances. Women, in particular, are undertaking staggering amounts of caregiving responsibilities which are not considered to be part of health care costs. What fails to be recognized is that as the cost to the state decreases, the cost to caregivers and families increases in both monetary and nonmonetary terms (Anderson & Elfert, 1989). It may be simply asking too much of some family members to take on all the responsibilities associated with this caregiving role in its present form. Programs are needed to help reduce the stress caregivers are experiencing. The present study along with other research suggests policy directions and program changes. These recommendations are as follows:

- Universal access to specialized head injury programs and services is recommended for all residents of Ontario.
• Current in-patient rehabilitation programs should be expanded to include specialized behavioral units to help the head-injured patient successfully reintegrate into the community and the family to learn appropriate behaviour management techniques.

• Systems of service delivery should be similar throughout each region or area of the province, with differences occurring in response to the particular needs of the community, rather than as a result of significant gaps in service, particularly in rural communities.

Research

1. A longitudinal study with a larger sample size, focusing on stressors and their effects on caregivers and information needs throughout the rehabilitation trajectory is recommended.

2. A Study focusing on all family members would increase knowledge about the impact of the head injury and its sequelae on different family members and on the family unit. Specific areas to be explored include similarities and differences in reactions among parents and spouses towards the head-injury experience, and the reactions and effects on children of parents with a head-injury.

3. With respect to future qualitative studies, the present study could be expanded by using a pure qualitative design to more
extensively explore caregivers' experiences in coping with a head-injury.

4. The immediate and long term financial costs to the family need to be described and quantified in more detail. In addition, a comparative study highlighting the experiences and costs of family caregivers with and without private insurance would provide insight into the relationship between formal support received and stresses experienced by the family.

5. The perception of what family caregivers feel constitutes good quality care is not well understood. Studies which elicit such perceptions could help health care professionals to more effectively meet the needs of family caregivers.

Conclusions

This study extends and supports much of the previous research about family caregivers for head injury adults. Even prior to discharge, the experience of having a relative with head injury was very distressing for family caregivers. Family caregivers reported issues of emotional and physical dependency, impatience, and dealing with the aversive and changed person as being the greatest sources of stress. Aggressive behaviour towards children and fear of physical violence upon discharge were highlighted by many of the
wives. Concerns about assuming and learning the caregiver role were prominent.

Interventions directed at these stresses may help to reduce the overall stress and enhance caregivers' ability to cope with their head-injured relatives' transition home. It is recommended that policies be developed related to the number and range of available services and resources for head injury victims and their families. Finally, standardized educational and support programs should be created to help meet the information and emotional needs of caregivers.
References


APPENDIX A

PATIENT DEMOGRAPHIC AND PRE-INJURY FORM

Demographic Information

DATE OF INJURY _________________

LENGTH OF TIME SPENT IN ACUTE CARE HOSPITAL (days) _____

LENGTH OF TIME SPENT IN REHABILITATION HOSPITAL (days) _____

TOTAL TIME SPENT IN BOTH HOSPITAL (ACUTE PLUS REHABILITATION) (days) _____

AGE: _____

SEX: _____ Male  _____ Female

DIAGNOSIS: Closed Head Injury _____

Multiple Trauma _____

Other _____

CAUSE OF INJURY: Motor Vehicle Accident _____

Fall _____

Sports Related Injury _____

Assault _____

Other _____

WITH WHAT CULTURE DO YOU FEEL MOST CLOSELY ASSOCIATED WITH? _________________
MARITAL STATUS (check one per column):

<table>
<thead>
<tr>
<th>Status</th>
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<th>Current</th>
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<tr>
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</tr>
<tr>
<td>Cohabitating, unmarried</td>
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<tr>
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<td></td>
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<tr>
<td>Separated</td>
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<tr>
<td>Divorced</td>
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<td></td>
</tr>
<tr>
<td>Widowed</td>
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<td></td>
</tr>
</tbody>
</table>

EMPLOYMENT STATUS (Check all that apply)

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<th>Status</th>
<th></th>
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</thead>
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<tr>
<td>Working, Full-Time</td>
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</tr>
<tr>
<td>Working, Part-Time</td>
<td></td>
</tr>
<tr>
<td>Homemaker</td>
<td></td>
</tr>
<tr>
<td>Student, Full-Time</td>
<td></td>
</tr>
<tr>
<td>Student, Part-Time</td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td></td>
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<tr>
<td>Disabled</td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td></td>
</tr>
</tbody>
</table>

ACCIDENT/MEDICAL INFORMATION

The following information will be obtained from the most reliable source (i.e., nurse, patient chart, care givers).
DURATION OF COMA (days) ______

(No eye opening, no following commands, no words, GCS 8 or less). Estimate number of days.

DURATION OF POST TRAUMATIC AMNESIA (days) ______

(Confused period during which ongoing events are not regularly registered and remembered.) Estimate number of days.

ADMISSION GLASGOW COMA SCALE (3-5): ________ (If on chart)

CT OR MRI ABNORMALITIES (check one):

___ None  ___ Bilateral

___ Left Hemisphere only  ___ Unknown

___ Right Hemisphere only

Specific localization (if known): ____________________________

BRAIN SURGERY:  _____ Yes  _____ No

Purpose (if known): ____________________________

OTHER DISABILITIES:

(e.g., spinal cord injury, blindness, amputation, etc.)

Specify: ____________________________

MOTOR WEAKNESS, PARALYSIS, SPASTICITY (check if appropriate)

_____ Right Side  _____ Left Side  ____ Not Applicable
HAVE YOU TAKEN YOUR RELATIVE ON WEEK-END PASSES PRIOR TO DISCHARGE? 

_______Yes _______No

WILL YOUR RELATIVE HAVE ANY COMMUNITY SUPPORTS UPON DISCHARGE?

_______Yes _______No Specify type if known:__________
APPENDIX B

FAMILY CAREGIVER'S DEMOGRAPHIC SHEET

Date of Interview____________________

Code Number ______

A. Informant's relationship to patient: (Circle one)

1. Mother 8. Niece or Nephew
2. Father 9. Cousin
3. Spouse/Partner 10. Friend
5. Sibling 12. Other_______
6. Grandparent
7. Aunt or Uncle

B. Sex of Informant: ______Male ______Female

C. How well is informant acquainted with patient's behaviour at present?

1. Hardly at all 4. Pretty well
2. Not so well 5. Very well
3. Fairly well

D. With what culture do you feel most closely associated? ________________
E. Employment Status (Check all that apply):

- Working, Full-Time
- Working, Part-Time
- Homemaker
- Student, Full-Time
- Student, Part-Time
- Retire
- Disabled
- Unemployed

F. Educational Level: (Circle the correct response)

1) 0 to grade 8
2) grade 9 to grade 12
3) grade 13 to community college/university
4) Graduate School
APPENDIX C

THE FAMILY CAREGIVER'S EXPERIENCE: OPEN-ENDED QUESTIONS

I would now like to ask you a few questions that will help me to get a better over-all picture of what the experience has been like as a care givers with a relative having a head injury. Take your time to answer these questions and feel free to add additional comments. I would like to tape your answers.

1. What kinds of things have caused the most uncertainty for you during your relatives illness experience?

2. What kinds of things do you find most concerning about taking your care givers home?

3. What impact has your relative's injury had on your life (Kay et al., 1988)?

   For example, how has your socialization with friends changed since the injury (Kay et al., 1988)? What kinds of household responsibilities have you had to take over that belonged to your relative prior to the injury (Kay et al., 1988)? What do you think are the financial effects to your family? What aspects of these changes has been most difficult for you to adjust to (Kay et al., 1988).

4. Is there anything else you would like to share with me at the present time about taking your care givers home.
APPENDIX D

EXPLANATION OF THE STUDY GIVEN TO THE FAMILY CAREGIVER BY THE NURSE

We have a registered nurse at the hospital today named Jane Merkley. She is working on a Master's degree in nursing at the University of Toronto. She is doing a study, under the supervision of Professor Joan Brailey, to find out what concerns caregivers have when they have a relative with a head injury. She is interested in the levels of stress and uncertainty in caregivers before their relative is discharged home from hospital. She is also interested in the information caregivers with a head-injured relative find most important to know in order to care for their relative at home.

Jane would like to meet with you so that she may describe the study and answer any questions you might have. You do not have to decide whether or not you wish to participate in this study until she has explained it to you.

If you agree to meet with Jane to learn more about the study, please understand that this does not commit you to participate. Your decision whether or not to participate will not influence the care you or your relative receives at the hospital.
Would you be willing to meet with Jane, so that she may explain the study and answer any questions?
Hello, Mr/Ms ________________, my name is Jane Merkley and I am a Registered Nurse presently studying at the University of Toronto in the Faculty of Nursing. Before going back to school I worked as a staff nurse, caring for people with head injuries. I am currently conducting a study under the supervision of Professor Joan Brailey from the Faculty of Nursing, which hopefully will help us to learn how nurses can help families to be more prepared for their relative's discharge from hospital. Specifically, I am interested in the kinds of information caregivers find important in the care of their relative at home. I am also interested in finding out what it is like for caregivers when they are about to take their relative home from hospital.

If you agree to take part in this study, I will ask you questions about yourself, such as how old you are, if you work or if you are married. I will ask you to complete three questionnaires. The questionnaires provide questions which may or may not apply to you. One of the questionnaires asks about uncertainty, another asks about information needs you may have in
order to care for your relative at home and the other asks about your stress related to your relative's injury. Your participation will take about 90 minutes of your time. To get some details about your relatives head injury, I would like to look at your relatives medical chart and ask you some questions to find out about your relative's injury, his/her treatment and other details such as his/her age, employment status, marital status etc. Finally, I will ask you four general questions which will allow you to expand on how you are feeling about your relative's illness and how this illness is affecting your life.

It is entirely your decision to take part in the study or not. Whatever your decision, the care of your relative will not be affected. At any time you may decide not to answer a question, or choose to end the interview. Your participation will not benefit you, however it may help nurses to assist future families in a similar situation.

If you choose to participate, neither your name, nor your relatives name, will be recorded with your answers. There will be not mention of any names or other means of identification in any report of the study.
Do you have any questions? Would you like to take part in this study? Thank you for your time. If you are willing to be a participant, I will need your signature on the consent form.
APPENDIX F

SUBJECT'S CONSENT FORM

(On Faculty of Nursing Letterhead)

I, ___________________, consent to participate in Jane Merkley's study about the information needs and experiences of a care giver with a relative who has sustained an injury to the head. I have had the opportunity to discuss this study with Jane Merkley and my questions have been answered to my satisfaction. I understand that this study is being undertaken under the supervision of Professor Joan Brailey, Faculty of Nursing at the University of Toronto.

I understand that I will be asked to complete three questionnaires before my relative's discharge home from hospital. The questionnaires ask about uncertainty, stress and information needs I have related to my relative's care upon discharge from hospital. I will also be asked general questions at the end of the interview about how the experience, of my relative's injury, has affected my life in general. In addition, some information will be obtained from myself including my age, sex, occupation and employment status. Also, information will be obtained from my relative's chart which will include his/her age, sex, marital
status, and medical information. The total time required for the interview will be 90 minutes.

I am aware that the study may not benefit me specifically, but the understanding gained may be helpful for families in the future.

I know that my name will not be recorded with my answers. Any information learned about me during the study will be confidential and neither my name nor any other identifying information will be made available to anyone other than the investigator or appear in any report of the study.

I consent to take part in this study with the understanding that I may withdraw at any time without my caregivers treatment being affected in any way.

If I have any further questions, I may call Jane Merkley at 928-6541.

I have been offered a copy of this form.

Dated at _____________ Hospital this _____ day of _____ 1992.

_________________________ _______________________
Participant's Name (please print) Participant's Signature

(Witness' Signature)
## Frequency of Items Perceived by Caregivers as Problematic and Caregivers’ Mean Strain Scores

<table>
<thead>
<tr>
<th>Freq.</th>
<th>Symptoms</th>
<th>Mean Strain</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>18</td>
<td>Impatience</td>
<td>3.75</td>
<td>2.1</td>
</tr>
<tr>
<td>16</td>
<td>Dependency on Others</td>
<td>3.90</td>
<td>2.6</td>
</tr>
<tr>
<td>15</td>
<td>Being forgetful, difficulty remembering</td>
<td>3.10</td>
<td>2.1</td>
</tr>
<tr>
<td>14</td>
<td>Changed Personality</td>
<td>3.40</td>
<td>2.5</td>
</tr>
<tr>
<td>14</td>
<td>Irritability</td>
<td>3.05</td>
<td>2.1</td>
</tr>
<tr>
<td>14</td>
<td>Fatiguing quickly</td>
<td>2.50</td>
<td>1.8</td>
</tr>
<tr>
<td>13</td>
<td>Difficulty planning &amp; organizing things</td>
<td>2.90</td>
<td>2.1</td>
</tr>
<tr>
<td>13</td>
<td>Difficulty remembering the right word</td>
<td>2.30</td>
<td>2.0</td>
</tr>
<tr>
<td>12</td>
<td>Difficulty setting realistic goals</td>
<td>2.90</td>
<td>2.2</td>
</tr>
<tr>
<td>12</td>
<td>Difficulty following through with things</td>
<td>2.80</td>
<td>2.2</td>
</tr>
<tr>
<td>12</td>
<td>Doing things slowly</td>
<td>2.70</td>
<td>1.7</td>
</tr>
<tr>
<td>12</td>
<td>Poor balance</td>
<td>2.70</td>
<td>1.5</td>
</tr>
<tr>
<td>12</td>
<td>Being easily distractible</td>
<td>2.40</td>
<td>1.8</td>
</tr>
<tr>
<td>11</td>
<td>Mood Swings, quick emotional shifts</td>
<td>2.80</td>
<td>2.1</td>
</tr>
<tr>
<td>11</td>
<td>Complaining about things</td>
<td>2.70</td>
<td>2.2</td>
</tr>
<tr>
<td>11</td>
<td>Poor concentration for extended periods</td>
<td>2.45</td>
<td>1.8</td>
</tr>
<tr>
<td>11</td>
<td>Lack of initiative</td>
<td>2.45</td>
<td>1.9</td>
</tr>
<tr>
<td>11</td>
<td>Anxiety/tension</td>
<td>2.30</td>
<td>1.8</td>
</tr>
<tr>
<td>11</td>
<td>Expressing self in a wordy, roundabout way</td>
<td>2.10</td>
<td>1.6</td>
</tr>
<tr>
<td>10</td>
<td>Needing Supervision</td>
<td>2.95</td>
<td>2.5</td>
</tr>
<tr>
<td>10</td>
<td>Depression</td>
<td>2.65</td>
<td>2.1</td>
</tr>
<tr>
<td>9</td>
<td>Temper Outbursts</td>
<td>2.85</td>
<td>2.6</td>
</tr>
<tr>
<td>9</td>
<td>Visual Problems</td>
<td>2.00</td>
<td>1.8</td>
</tr>
<tr>
<td>9</td>
<td>Apathy, lack of interest in things</td>
<td>2.30</td>
<td>1.8</td>
</tr>
<tr>
<td>9</td>
<td>Restlessness</td>
<td>2.15</td>
<td>1.7</td>
</tr>
<tr>
<td>9</td>
<td>Difficulty speaking smoothly and clearly</td>
<td>1.95</td>
<td>1.5</td>
</tr>
<tr>
<td>8</td>
<td>Difficulty bringing emotions under control</td>
<td>2.90</td>
<td>2.5</td>
</tr>
<tr>
<td>8</td>
<td>Getting Bored Easily</td>
<td>1.90</td>
<td>1.7</td>
</tr>
<tr>
<td>6</td>
<td>Loneliness</td>
<td>2.00</td>
<td>1.8</td>
</tr>
<tr>
<td>6</td>
<td>Headaches</td>
<td>1.60</td>
<td>1.5</td>
</tr>
<tr>
<td>5</td>
<td>Getting into arguments with others</td>
<td>2.15</td>
<td>2.1</td>
</tr>
<tr>
<td>3</td>
<td>Low Sex Drive</td>
<td>1.75</td>
<td>1.9</td>
</tr>
<tr>
<td>2</td>
<td>High Sex Drive</td>
<td>1.40</td>
<td>1.4</td>
</tr>
<tr>
<td>1</td>
<td>Being physically violent</td>
<td>1.15</td>
<td>0.7</td>
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</table>
## APPENDIX H

**Additional Stresses Identified by Family Caregivers**

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<thead>
<tr>
<th>Stresses</th>
<th>Frequency</th>
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</thead>
<tbody>
<tr>
<td>1. Living and Dealing with the Changed Person</td>
<td></td>
</tr>
<tr>
<td>- Dealing with unusual behaviors and dependency needs</td>
<td>7</td>
</tr>
<tr>
<td>- Concern about aggression towards children</td>
<td>5</td>
</tr>
<tr>
<td>- Concern for the physical safety and emotional well-being of the head-injured person.</td>
<td>7</td>
</tr>
<tr>
<td>2. Additional Responsibilities and Altered Family Roles</td>
<td></td>
</tr>
<tr>
<td>Concern about ability to cope with the demands of role</td>
<td>11</td>
</tr>
<tr>
<td>- Acquisition of new roles within the family</td>
<td>8</td>
</tr>
<tr>
<td>- Concern about learning the caregiver role</td>
<td>8</td>
</tr>
<tr>
<td>3. Lack of Information, Professional Support and Community Resources</td>
<td></td>
</tr>
<tr>
<td>- Lack of specific tailored information for caregivers</td>
<td>7</td>
</tr>
<tr>
<td>- Concern that lack of knowledge will lead to</td>
<td>10</td>
</tr>
<tr>
<td>neurological and physical regression.</td>
<td></td>
</tr>
<tr>
<td>- Relating to health care professionals</td>
<td>7</td>
</tr>
<tr>
<td>- Lack of community and professional support</td>
<td>7</td>
</tr>
<tr>
<td>Area</td>
<td>Frequency</td>
</tr>
<tr>
<td>------------------------------------------------</td>
<td>-----------</td>
</tr>
<tr>
<td>1) Negative Emotional States</td>
<td>16</td>
</tr>
<tr>
<td>- Feelings of guilt, anger, isolation, fatigue</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>- Feelings of depression, anxiety, and loss of control</td>
<td>8</td>
</tr>
<tr>
<td>- Anger and hostility towards the head-injured person</td>
<td>5</td>
</tr>
<tr>
<td>2) Physical Health Problems in the Caregiver</td>
<td>10</td>
</tr>
<tr>
<td>3) Disruption of the Caregivers Social Life</td>
<td>18</td>
</tr>
<tr>
<td>- Behavioural changes reducing social activities</td>
<td>6</td>
</tr>
<tr>
<td>- Fatigue reducing caregivers' ability to socialize</td>
<td>5</td>
</tr>
<tr>
<td>- Fear of embarrassment or stigma</td>
<td>3</td>
</tr>
<tr>
<td>- Feeling trapped</td>
<td>15</td>
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<tr>
<td>4) Disruption in Family and Marital Relationships</td>
<td>20</td>
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<tr>
<td>- Uncertainty related to the future of the marriage</td>
<td>7</td>
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<tr>
<td>- Difficult relationships with extended families</td>
<td>4</td>
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<tr>
<td>5) Financial Difficulties</td>
<td>15</td>
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</table>
Frequency Distribution of Total FCUIS Scores

Number of Subjects

Total Scores on FCUIS
<table>
<thead>
<tr>
<th>Data</th>
<th>Pearson's R Correlation (r=)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Length of time in acute care</td>
<td>.11</td>
<td>.63</td>
</tr>
<tr>
<td>Length of time in rehab</td>
<td>.34</td>
<td>.14</td>
</tr>
<tr>
<td>Total time in hospital</td>
<td>.22</td>
<td>.34</td>
</tr>
<tr>
<td>Length of PTA</td>
<td>.41</td>
<td>.08</td>
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<tr>
<td>Length of time in coma</td>
<td>.37</td>
<td>.11</td>
</tr>
<tr>
<td>Glasgow Coma Score</td>
<td>-.23</td>
<td>.34</td>
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<tr>
<td>Age</td>
<td>-.11</td>
<td>.63</td>
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</table>

**Test of Difference between Demographic Data and FCUIS Scores**

<table>
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<tr>
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<th>T-Test</th>
<th>P-value</th>
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<tr>
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<td>.29</td>
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<tr>
<td>Sex of Caregiver</td>
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<td>.70</td>
</tr>
<tr>
<td>Patient's Sex</td>
<td>1.3</td>
<td>.70</td>
</tr>
<tr>
<td>Operative Procedure</td>
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<td>.20</td>
</tr>
<tr>
<td>Education level of Caregiver</td>
<td>1.5</td>
<td>.53</td>
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</table>
APPENDIX L

Caregiver Reports of Uncertainty at the Time of Discharge from Rehabilitation and their frequencies

<table>
<thead>
<tr>
<th>Reports</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Uncertainty about immediate and long term recovery</td>
<td>20</td>
</tr>
<tr>
<td>- Uncertainty about the extent of mental or cognitive dysfunction</td>
<td>16</td>
</tr>
<tr>
<td>- Concern about the head-injured patient’s future</td>
<td>14</td>
</tr>
<tr>
<td>- What the future holds for the family and the caregiver</td>
<td>12</td>
</tr>
<tr>
<td>2) Uncertainty about Resources</td>
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<tr>
<td>- Long-term financial implications and ability to access needed services</td>
<td>18</td>
</tr>
<tr>
<td>- Lack of information contributing to uncertainty</td>
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</table>
Frequency Distribution of Total CINQ Scores
### Pearson's R Correlation Scores for Demographic and Injury Related Data and CINO Scores

<table>
<thead>
<tr>
<th>Data</th>
<th>Pearson’s R Correlation (r=)</th>
<th>P-value</th>
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</thead>
<tbody>
<tr>
<td>Length of time in acute care</td>
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<td>.23</td>
</tr>
<tr>
<td>Length of time in rehabilitation</td>
<td>.50</td>
<td>.02</td>
</tr>
<tr>
<td>Total time spent in hospital</td>
<td>.41</td>
<td>.07</td>
</tr>
<tr>
<td>Length of Post-traumatic amnesia</td>
<td>.52</td>
<td>.02</td>
</tr>
<tr>
<td>Length of time in coma</td>
<td>.57</td>
<td>.01</td>
</tr>
<tr>
<td>Glasgow coma score</td>
<td>.02</td>
<td>.95</td>
</tr>
<tr>
<td>Age</td>
<td>.14</td>
<td>.54</td>
</tr>
</tbody>
</table>

### T-test for Differences between Demographic Data and CINO Scores

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<tr>
<th>Data</th>
<th>T-Test</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship to patient</td>
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<td>.23</td>
</tr>
<tr>
<td>Sex of caregiver</td>
<td>.87</td>
<td>.41</td>
</tr>
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<td>Patient's sex</td>
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<td>Education level of Caregiver</td>
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