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**FINDING MEANING AFTER A HEAD INJURY: THE EXPERIENCE OF
PATIENTS' MOTHERS AND WIVES DURING THE
EARLY PHASE OF RECOVERY.**

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A thesis submitted to the Faculty of Graduate Studies and Research in partial
fulfilment of the requirements for the degree of Doctor of Philosophy

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ABSTRACT

A head injury is an unexpected and potentially life-threatening event that frequently results in physical, cognitive, and emotional changes in the patient. As a result, a head injury affects the whole family, and mothers and wives may be potentially at risk because they tend to assume the primary caregiving role post-trauma. Current thinking is that a person's ability to restore a sense of meaning in life is an important aspect of psychological adjustment following the traumatic injury of a loved one. However, little is currently known about the process of finding meaning during the early phase of recovery. The purpose of this qualitative study was therefore to generate a theory about how mothers and wives find meaning during the early phase of recovery following the head injury of their loved one.

Grounded theory methodology was used to explore the experience of 5 mothers and 9 wives whose family member had suffered a moderate or severe head injury. Participants were recruited from three major Level I Canadian trauma centres using inclusion criteria and theoretical sampling to achieve theoretical completeness. They were interviewed on two occasions: 1 to 5 weeks and again 6 to 8 weeks following their family member's head injury. Iterative analysis and constant comparative methods were used throughout the study and the data revealed a process of finding meaning embedded in three distinct phases: "Focusing on the here and now", "Expanding perspective", and "Resuming life". The process of finding meaning was characterized by an emerging fit between the participants' perception of their current situation and their pre-trauma value and belief system. This process helped participants to find a new way of thinking about their world and to find a new order and sense of direction in their lives.

The findings of this study augment our theoretical understanding of family members' psychological responses to traumatic events, and may be helpful to guide nursing care of the whole family during the early phase of recovery following a head injury.

RÉSUMÉ

Un traumatisme crânien est un événement traumatisant qui présente des changements physiques, cognitifs, et émotionnels chez le patient. Ces changements affectent toute la famille, et les épouses et les mères ont le potentiel d'être plus à risque car elles ont tendance d'assumer la responsabilité des soins. La capacité de la personne à trouver un sens à l'événement semblerait être un aspect important de l'ajustement psychologique de la personne suite à un événement traumatisant qui implique un membre de la famille. À date, il y a peu de connaissances à ce sujet donc le but de cette étude était de développer une théorie explicative du processus où les mères et les épouses de patients atteints d'un traumatisme crânien trouvent un sens à l'événement. La méthode d'analyse par theorization ancrée a été utilisée dans cette étude pour explorer l'expérience de 5 mères et de 9 épouses de patients atteints d'un traumatisme crânien sévère ou modéré. Les participantes ont été recrutées de trois centres canadiens de traumatologie du niveau I, basé sur des critères de sélections et d'échantillonnage théorique. Les entrevues ont eu lieu à deux temps, soit 1 à 5 semaines et 6 à 8 semaines suivant le traumatisme crânien du patient. Les techniques d'analyse itérative et de comparaison constante ont été employées tout au long de l'étude. Les données ont révélé un processus de trouver un sens à l'événement qui était encadré par les trois phases suivantes : "Focusing on the here and now", "Expanding perspective", et "Resuming life". Ce processus était caractérisé par un lien émergent entre la perception des participantes face à leur situation actuelle en relation à leur système de valeurs et croyances antérieures. Ce processus a permis aux participantes de trouver une nouvelle façon de conceptualiser leur monde et de trouver un nouvel ordre et un nouveau sens de direction à leur vie.

Les résultats de cette étude augmentent notre compréhension théorique de l'ajustement psychologique des familles suite à un événement traumatisant. Ces connaissances pourraient être utiles pour guider les soins infirmiers de la famille pendant la phase de récupération d'un patient atteint d'un traumatisme crânien.

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CHAPTER 1 - INTRODUCTION

Statement of the Problem

In Canada, an estimated 37,000 persons suffer a traumatic brain injury each year and Ontario and British Columbia each reported a total of 14,000 hospital admissions as a result of traumatic intra-cranial injuries (Statistics Canada, 1996). Brain Injury is the number one killer and disabler of people under the age of 45 in Canada (Brain Injury Association of British Columbia, 2002). Males suffer head injuries at about twice the rate of females and about half of all patients are between the ages of 15 and 34 (Canadian Brain Injury Coalition, 1999). A head injury is an unexpected and potentially life-threatening event that frequently results in permanent functional and cognitive disabilities, inability to work, and live independently (Bond, 1984; Brooks, 1984a; Oddy, 1984).

Although the majority of studies have focused on the head-injured patient's cognitive as well as physical adjustment to the accidental injury, a few studies have begun to investigate the post-trauma reactions of family members (Gervasio & Kreutzer, 1997; Hall, Karzmark, Stevens, Englander, O'Hare, & Wright, 1994; Livingston, Brooks, & Bond, 1985 a, 1985 b; McKinlay, Brooks, Bond, Martinage, & Marshall, 1981; Oddy, Humphrey, & Uttley, 1978). The study findings indicate that an estimated 39% to 69% of family members of the head-injured patient experience emotional distress, depression, and anxiety in the first year after an accidental injury. The majority of these family members were reported to be mothers and wives of the head-injured patient as women typically assume the caregiver role following a head injury (Gervasio & Kreutzer, 1997; Hall et al., 1994; Livingston et al., 1985). Consequently, mothers and wives are at potential risk for developing psychological problems following their relative's head injury (Hall et al., 1994; Hammell, 1994; Kravetz, Gross, Weiler, Ben-Yakar, Tadir, & Stern, 1995; Livingston et al., 1985 a, 1985 b; Oddy et al., 1978; Rivara, Gayle, Jaffe, Polissar, Shurtleff, & Margin, 1992; Rosenbaum & Najenson, 1976).

Current thinking is that the person's ability to restore a sense of meaning in life is an important aspect of psychological adjustment following the traumatic

injury of a loved one and begins during the early post-trauma period (Thompson & Janigian, 1988). However, little is currently known about the process of finding meaning post-trauma. Therefore, the purpose of this qualitative study was to generate a theory about the process of finding meaning during the early phase of recovery following the head injury of a family member. A clearer understanding of this process during the early phase of recovery would enable the nurse to more precisely assess the psychological adjustment of family members and to develop early interventions that support family members in restoring a perceived sense of meaning.

Theoretical Framework

A number of related frameworks were reviewed. The McGill Model of Nursing provided a beginning orientation for the study. This model is based on the premise that people can potentially rally from the negative effects of stressor events such as a head injury (Gottlieb & Rowat, 1987). According to the McGill Model of Nursing, health involves processes of development, learning, and coping in which the emphasis is on goal-oriented behaviours that provide a sense of purpose and meaning (Gottlieb & Rowat, 1987). Thompson and Janigian's theory (1988) was also explored as it extends the McGill Model's notions of purpose and meaning in that it describes how purpose and meaning are related. Specifically it conceptualizes meaning in terms of having a sense of order and purpose. Whereas order pertains to notions of stability and predictability that allow for planning to occur, purpose relates specifically to having goals and goal-directed behaviours. When a traumatic event such as a head injury occurs, a person's sense of meaning may be called into question. According to cognitive processing theory (Horowitz, 1986), a person attempts to assimilate the trauma event into their cognitive schema. The person's cognitive schema is thought to represent his or her most basic assumptions about the world and place in it (Janoff-Bulman, 1992). When the trauma event is incongruent with the person's most basic world assumptions, cognitive efforts are aimed at reconstructing the schema such that it can accommodate the event (Horowitz, 1986; Janoff-Bulman, 1992). According to Thompson and Janigian (1988), a sense of meaning is restored in part by the use of attributional statements. Attributions are

thought to clarify and re-frame what happened into a context that may be compatible with the person's assumptions and beliefs, and as such, assist people in understanding their world and in attaining personal goals (Weiner, 1985). As the person's mind engages in this cognitive work, he or she experiences intrusions and avoidance reactions, as well as feelings of emotional distress (Horowitz, 1986; Janoff-Bulman, 1992; Thompson & Janigian, 1988). These reactions are thought to be healthy indicators of cognitive processing. However, they are thought to become unhealthy if they persist more than 4 weeks following a traumatic event (Horowitz, 1986). In the McGill Model of Nursing, the family plays a central role in promoting healthy processes. Of particular interest to this study is that the family helps members to manage stressors by mobilizing personal and particularly social resources.

In summary a number of theoretical perspectives that relate to the process of finding meaning following a trauma event have been identified in the literature. However, these have not been integrated into a model directly applicable to clinical practice. Therefore this study used grounded theory methodology (Artinian, 1988; Strauss & Corbin, 1997) with the purpose of extending, refining, and/or altering the above theoretical assertions about the process of finding meaning as they apply to nursing practice with family members of the head-injured. Artinian (1988) describes this use of grounded theory as "the emergent fit mode" (p. 143).

Several assumptions underlying the use of grounded theory methodology were explicitly considered in the study (Strauss & Corbin, 1997): a) the need to ground the theory in data in order to fully explain the complexity and variability of the phenomenon; b) the belief that persons are actors who take an active role in responding to problematic situations; c) the realization that persons act on the basis of meaning; d) the understanding that meaning is defined and redefined through interaction; e) a sensitivity to the evolving and unfolding nature of events (process); and f) an awareness of the interrelationships among conditions (structure), responses (process), and consequences. It is important to emphasize that although an emergent fit mode was used in this study, the theoretical perspectives outlined previously constituted a starting place for exploring the process of finding meaning. Blumer (1969) described, the comparative analysis techniques of the grounded

theory method needs to allow the data and empirical world to "talk back" to each other. Therefore, as the participants' stories unfolded, the emerging themes were compared and contrasted with the literature using constant comparative analysis techniques and caution was taken to ensure that theoretical views were not imposed on the data.

CHAPTER 2 - REVIEW OF THE LITERATURE

Although little is known about the process of finding meaning following a traumatic event, several related variables have been discussed in the literature. The following body of literature was initially reviewed: the trauma literature and, more specifically, the literature on head injury, cognitive processing, meaning, attribution, and social support. This literature review was organized according to the elements of a paradigm (Strauss & Corbin, 1998). These are the *conditions* that define trauma events, variables thought to be part of a person's *psychological responses* to a trauma event, and *consequences* or indicators of the person's psychological adjustment to a trauma event. Additional literature was accessed through constant comparative techniques as it became relevant to emerging themes in the data (Glaser & Strauss, 1967; Strauss & Corbin, 1997).

Conditions that Define Trauma Events

Conditions have been defined as "sets of events or happenings that create the situations, issues, and problems pertaining to a phenomenon and, to a certain extent, explain why and how persons or groups respond in certain ways" (Strauss & Corbin, 1998, p. 130). Of interest to this study was the occurrence of a traumatic life event in a person's life. Such events have been reported to initiate a search for meaning, a process central to psychological adjustment (Thompson & Janigian, 1988). A traumatic life event has been conceptualized as an unexpected life threatening experience that lies outside the normal range of human experiences causing intense fear, terror, and a sense of helplessness (APA, 1994; Janoff-Bulman, 1992). Studies of traumatic events have included criminal victimizations such as rape and assault, natural disasters such as earthquakes and floods, human-induced disasters such as nuclear accidents, military combat, torture and concentration camps, and life-threatening illnesses (Colin, Taylor, & Skokan, 1990; Davidson & Baum, 1986; Feinstein & Dolan, 1991; Shalev, 1992; Shalev, Peri, Canetti, & Schreiber, 1996; Silver, Boone, & Stones, 1983; Strohmyer, Norian, Patterson, & Carlin, 1993). In particular, a head injury has been regarded as

potentially traumatic since it may result in physical, cognitive, behavioural, and psychosocial deficits (McFarlane, 1988b; Oddy et al., 1978; Tate, Lulham, Broe, Strettles, & Pfaff, 1989). Such events not only affect the patient but the entire family as well. Family theorists have conceptualized such situations as non-normative life events (Lavee, McCubbin, & Olson, 1987; McCubbin, Joy, Canble, Comeau, Patterson, & Needle, 1980). Non-normative family events that have been studied include: natural disasters (Dollinger, 1986), post-war reunions (Maloney, 1988; Solomon, 1988; Verbrosky & Ryan, 1988), chronic illness (Eiser, Havermans, & Eiser, 1995; Heiney, Neuberg, Myers, & Bergman, 1994), and critical injuries (Baker, 1990; Cavallo, Kay, & Ezrachi, 1992; Cella, Perry, Kulchysky, & Goodwin, 1988). These events are thought to have an impact on the whole family (Figley, 1989; Hill, 1949; McCubbin et al., 1980) and there is ample clinical evidence that the head injury of a family member impacts the entire family system.

Types of Conditions

Three types of conditions have been described by Strauss & Corbin (1998). These are causal conditions, intervening conditions, and contextual conditions.

Causal Conditions

Unexpected events such as the head injury of a family member are considered causal conditions to which the person must respond. Little attention has been given to the relationship between the nature of the event and the responses of victims and their family members following a trauma event. In fact, a number of trauma studies have sampled participants who had experienced a variety of trauma situations without defining and examining the nature of the trauma event itself (Frutiger, Ryf, Bilat, Rosso, Furrer, Cantieni, Ruedi, & Leutenegger, 1991; Glancy, Glancy, Lucke, Mahurin, Rhodes, & Tinkoff, 1992; Grossman, 1995; MacKenzie, Shapiro, Smith, Siegel, Moody, & Pitt, 1987; Shalev et al., 1996; Van Dongen, Veltman, Bostrom, Buechler, & Blostein, 1993). Similarly, no studies with family members of head-injured patients were found that considered the cause of the injury in relation to

psychological responses post trauma. Studies with family members of the head-injured have tended to focus on the traumatized patient as the source of the family's stress (Brooks, Campsie, Symington, Beattie, & McKinlay, 1986; McKinlay et al., 1981; Rosenbaum & Najenson, 1976). However, little is known about how the patient's deficits relate to the family member's post-trauma responses. Moreover, these studies have tended to focus on the months and years that follow the patient's injuries and little is known about the family's perception of the patient during the early phase of recovery. There is therefore a need to understand how the causal nature of the event and of the patient's deficits relates to the person's post-trauma responses and their ability to find meaning in the event.

Intervening Conditions

The second type of condition defined by Strauss and Corbin (1998) are intervening conditions. Intervening conditions are those that mitigate the impact of causal conditions on the consequences of a traumatic event. Three intervening conditions were reviewed that may have theoretical significance in explaining in part why some people adjust more easily than others to a trauma event. These are socio-economic status, negative life events, and the quality of social relationships prior to the trauma event.

Education, occupation, and income are important aspects of the socio-economic profile of the individual (Alder, Boyce, Chesney, Folkman, & Syme, 1993; Alder et al., 1994). People from higher socio-economic classes suffer from less disease, and have lower levels of morbidity and mortality risk compared with the more disadvantaged (Alder et al., 1993). Likewise, high income and education levels in victims of traumatic injuries have been related to good psychological adjustment (Atkeson, Calhoun, Resick, & Ellis, 1982; Glancy et al., 1992; Landsman et al., 1990; MacKenzie, Siegel, Shapiro, Moody, & Smith, 1988; Shalev et al., 1996). Glancy et al. (1992) attributes the relationships between socio-economic status and psychological adjustment to the problem-solving abilities of highly educated people.

In contrast, few studies with family members of traumatized patients have examined the relationship between socio-economic status and psychological adjustment. Only two studies could be located and findings indicate no significant relationship between socio-economic status and measures of psychological well-being, emotional distress and depression (Downey, Silver, & Wortman, 1990; Grossman, 1995). Furthermore, these relationships have not been explored with family members of the head-injured as socio-economic indicators such as income, education level, and employment status have been used to describe the sample rather than as correlates of psychological adjustment (e.g. Hall et al., 1994; Livingston et al., 1985a). Because of the possibility that socio-economic status may influence a person's problem-solving ability and their post-trauma reactions, there is a need to consider these indicators as intervening conditions in the process of finding meaning.

A person's previous experience with negative life events is another intervening condition that has been reported to potentially influence post-trauma outcomes. Grossman (1995) found that sources of stress experienced in the year prior to a critical injury were positively associated with poor psychological adjustment in the trauma patient and his family members, as measured by the amount of direct and non-direct support received, and the level of psychological well-being. Similarly, women with major negative life changes prior to their rape were found to be more traumatized one year later compared to women with minor life changes (Ruch, Chaldner, & Harter, 1980). Moreover, victims of a bush fire with Post-Traumatic Stress Disorder (PTSD) were found to have experienced a higher number of adverse life events both before and after the fire than victims who did not have PTSD (McFarlane, 1988a). No studies with family members of the head-injured have examined the presence of previous negative life events in relation to post-trauma adjustment. Together, these findings call for a better understanding of the role that previous negative life events play in the process of finding meaning.

The third intervening condition that may potentially influence post-trauma reactions is the quality of the person's social relationships prior to the accident. Convergent evidence from the support literature suggests that low levels of support

prior to a traumatic event is associated with increased psychiatric symptomatology after an accident (For reviews, see: House, Umberson, & Landis, 1988; Toits, 1995). Furthermore, it has been suggested that pre-existing problems in the family's relationships may be exacerbated by the head injury of a family member, and contribute to poor psychological adjustment following the accident (Florian, Katz, & Lahav, 1991; Martin, 1988; Resnick, 1983; Rivara et al., 1992). However, no trauma study was located that considered the quality of the family's social relationship with the patient prior to the accident. However, one study with 78 wife caregivers of men with irreversible memory impairment found past marital adjustment to be significantly related to participant burden following the accident (Robinson, 1990). There is therefore a need to further understand the role of the pre-trauma relationship in the process of finding meaning.

Contextual Conditions

The third type of condition identified by Strauss and Corbin (1998) are contextual conditions. Contextual conditions are patterns of conditions situated in time and place to create the circumstances of problems to which the person responds. These conditions have their source in causal and intervening conditions and how they combine into various pattern dimensions. The contextual conditions surrounding the trauma event have not tended to be systematically examined in the general trauma literature. However, a small body of literature has identified contextual factors that result from the head injury of a family member. These factors include: an uncertain prognosis (Ewing-Cobbs & Fletcher, 1987; Martin, 1988; Prigatano, 1987), the patient's physical deficits (Kay & Lezak, 1990), caregiving burden (Brooks et al., 1986; Robinson, 1990), the energy demands of long-term rehabilitation programs (Martin, 1988), financial burden and loss of employment (Hall, et al., 1994), and problems with social relationships (Livingston et al., 1985 b; Rogers, 1984; Rosenbaum & Najenson, 1976; Thompson, 1984). The cognitive and behavioural changes in the patient have been identified as most difficult for family members to cope with (Hendryx, 1989; Rosenthal & Bond, 1990; Thompson, 1984).

There is also evidence that contextual conditions may be qualitatively different for mothers and wives of head-injured patients. One major stressor for mothers of the head-injured is dealing with the patient's dependent and childish behaviours (Florian et al., 1991). Mothers are most frequently the primary caregiver for their adult child's physical and psychological needs (Brooks et al., 1986; Livingston et al., 1985 a, 1985 b; Panting & Merry, 1972) although they often share these responsibilities with a husband/partner and other children. The burden of caring for the patient has been thought to intensify if the mother is separated or divorced or if her husband does not assist with the care (Martin, 1988).

Similarly, wives of the head-injured have reported difficulty in accepting regressive behaviours in their spouse (Brooks, 1984b; Rosenbaum & Najenson, 1976). However, a few studies have reported that wives experience more burden than mothers in meeting the emotional and physical demands of caring for their head-injured family member (Panting & Merry, 1972; Thompsen, 1974). Specifically, their spouse's emotional lability and cognitive deficits make sharing decisions and family responsibilities difficult. As a result, wives must often cope with these obligations alone (Panting & Merry, 1972; Rosenbaum & Najenson, 1976; Thompsen, 1974; Thompsen, 1984).

One limitation of these studies is that they have tended to reflect the participants' experience months and years following their loved one's head injury. Very little is known about the role that contextual factors play in the person's adjustment during the early post-trauma period, and their ability to derive meaning about the event.

Summary

Causal, intervening and contextual conditions that could potentially play a role in the person's ability to restore meaning following the traumatic head injury of a family member were reviewed. Trauma studies and, more specifically, studies with family members of the head-injured, have tended not to explore the relationship of these variables to the person's post-trauma adjustment systematically. Moreover, study findings have been mixed. There is therefore a need to be mindful of

emerging causal, intervening, and contextual conditions in the data and the role that they play in the process of finding meaning during the early post-trauma period.

Psychological Responses To Trauma Events

Personal and social resources are thought to shape the person's cognitive appraisal and responses following a stressful event (Moos & Shaefer, 1993). One personal resource found to play a role in the person's ability to restore a sense of meaning is the attributions that a person makes to explain an event. According to Weiner (1985), people are motivated to make attributions that assist them in understanding their world and in attaining personal goals. The general trauma literature on attributions was reviewed to clarify definitions as well as the relationships between attributions, conditions, and consequences of traumatic events. The head injury literature was also reviewed for attribution studies that included family members.

In addition, considerable attention has been given to social resources and their contribution to psychological adjustment following traumatic event (Brown & Harris, 1978; Cobb, 1976; Cohen & Wills, 1985). More specifically, it would appear that the quality of the person's social relationships is a dimension of support that is critically important to a person's psychological adjustment during the early phase of recovery following a traumatic event (Harvey, Orbuch, & Fink, 1990; Harvey, Orbuch, Weber, Merbach, & Alt, 1992; Hewstone, 1989; Janoff-Bulman, 1992). The literature on social resources was reviewed for its relationships to conditions, and consequences of traumatic events. The head injury literature was also reviewed for studies with family members that have included social resources as a variable.

Attributions

Attributions refer to explanations that are given for an event (Bell-Gredler, 1986). Attributions are most commonly made following traumatic life events such as natural disasters (Dollinger, 1986), rape (Janoff-Bulman, 1979; Silver et al., 1983), the loss of a significant other (Schwartzberg & Janoff-Bulman, 1991),

critical injury (Bulman & Wortman, 1977; Heinemann, Bulka, & Smetak, 1988; Van Den Bout, Van Son-Schoones, Schipper, & Groffmen, 1988), and serious illness (Affleck, Allen, Tennen, McGrade, & Ratzan, 1985; Berkman & Austin, 1993; Lowery, Jacobsen, & Murphy, 1983; Taylor, Lichtman, & Wood, 1984; Tennen, Affleck, & Gershman, 1986; Thompson, 1991). Attributions have been measured in terms of the whether or not an attribution was generated, and the type of explanation generated by a person for the cause of a traumatic event.

Generating Attributions

Studies have shown that 90 - 100 % of victims generate specific attributions for the cause of a traumatic event (Affleck et al., 1985; Bulman & Wortman, 1977; Du Cette & Keane, 1984; Gotay, 1985; Heinemann et al., 1988; Lowery & Jacobsen, 1984; Lowery et al., 1983; Taylor et al., 1984; Tennen et al., 1986). Although the association between making attributions and psychological adjustment has been understudied, a small group of comparative studies have found patients who were concerned with making attributions for the cause of an event reported higher levels of emotional distress and intrusive/avoidance reactions compared to those who did not have this concern (Dollinger, 1986; Lowery, Jacobsen, & DuCette, 1993; Lowery & Jacobsen, 1984). In contrast, other studies have found no relationship between making an attribution for the cause of a traumatic event and measures of psychological adjustment (Lowery, Jacobsen, & McCauley, 1987; Taylor et al., 1984) and one study with 30 rehabilitation patients with a spinal cord injury reported that a concern with finding the cause of an accident was reported to be significantly related to high self-esteem (Van Den Bout et al., 1988). In order to explain the variability in study findings, more attention was given to the type of attribution generated.

Types of Attributions

Thompson (1991) reviewed the literature and classified attributions into three categories: attributions about why the event occurred (causal attributions), attributions about why the event occurred to the person specifically (attributions

about selective incidence), and attributions about who was responsible for the event (attributions of responsibility). Although promising at the time, this approach has continued to yield confusing research findings.

A number of studies have examined attributions about why the traumatic event occurred (Affleck, Tennen, Croog, & Levine, 1987a, 1987b; DuCette & Keane, 1984; Tennen, Affleck, Allen, McGrade, & Ratzan, 1984; Tennen et al., 1986), and the findings have been mixed. One reason for the variability in the findings may be that the cause for an illness or traumatic event may hold a different meaning for the person. For example, heredity may make one person feel less guilty since they were not to blame for their illness, whereas heredity may make another person feel frustrated by the lack of control over their health. Furthermore, attributions generated for why the event has occurred may depend on the specific context of the traumatic event and the person's unique explanations.

Only a few studies were found that examined attributions of selectivity (i.e., asking the question "why me?") (Lowery et al., 1987; Thompson, 1991; van den Bout et al., 1988). Results indicate that a concern about selective incidence was related to poor psychological adjustment. However, caution is indicated in interpreting these results given the small number of studies.

Attributions of responsibility have received the most attention in the literature and these studies have also produced mixed results. Some studies have found concerns for self-responsibility to be related to poor psychological outcomes (Downey et al. 1990; Dollinger, 1986; Timko & Janoff-Bulman, 1985), while others have found self-responsibility to be associated with good psychological outcomes (Bulman & Wortman, 1977; Tennen et al., 1984), or to have no association to psychological adjustment (Croog & Richards, 1977; Heineman, Bulka, & Smetak, 1988; Sholomskas, Steil, & Plummer, 1990; Taylor et al., 1984; Witenburg et al., 1983).

A lack of a clear pattern of relationship between the different types of attributional statements and levels of psychological adjustment pointed to a need to consider the concept of attributions from a new perspective. Weiner (1985) postulated that the type of causal attribution that is made might be less important than the common

dimensions underlying the attribution. Three causal dimensions have been described by Weiner (1979): locus of causality (i.e., whether the cause of the event resides within or is external to the person), stability (i.e., whether the cause of the event is invariant or changeable over time), and controllability (i.e., whether the cause of the event is controllable or uncontrollable by the person). Studies that have examined causal dimensions (Berkman, & Austin, 1993; Falsetti, & Resnik, 1995; Frazier, 1990; Gold, 1986; Lowery & Jacobsen, 1984) have also produced confusing results. One problem with these studies is that the causal dimensions related to a specific event have been difficult to interpret across participants. People described causal dimensions in different ways even when the traumatic event was similar in nature. Furthermore, there is a lack of valid and reliable instruments that measure causal dimensions, leading to a lack of useful clinical results from these studies. These issues may explain why causal dimensions have been largely ignored in the trauma literature.

Attributions in Families of Traumatized Persons

Only a few studies have examined the attributions made by family members following a traumatic event that involved a relative. These studies consisted of family members of patients with cancer (Eiser et al., 1995; Gotay, 1985), stroke (Thompson, 1991), schizophrenia (Natale & Barron, 1994), the sudden death of an infant (Downey et al., 1990), and a soccer accident (Dollinger, 1986). Like the patient-focused studies, 80% to 90% of family members were found to generate an attribution for the cause of a relative's trauma. Similarly there was no clear trend explaining the relationship between generating attributions and psychological outcomes. Furthermore, the family-based studies that have examined types of attributions (Dollinger, 1986; Downey et al., 1990; Gotay, 1985; Thompson, 1991) and their causal dimensions (Natale & Barron, 1994) have also produced mixed results suggesting the need to examine attribution from a new perspective. No attributional studies of family members of the head-injured have been found.

In conclusion, two decades of attribution research have yielded few clinically applicable results. This may be because attributional statements are multidimensional and context dependent. Therefore they should not be examined as

isolated entities but rather, their role should be examined in the context of a process of restoring meaning following a trauma event. Furthermore, there is some evidence that attribution-making may be embedded into the person's social context (Harvey et al., 1990; Thompson & Janigian, 1988). One aspect of the social context that has attracted attention because of its intervening role in the stress process is a person's social relationships.

Social Relationships

Social relationships may be conceptualized in terms of social integration, social networks, and the quality of social relationships (House et al., 1988). The quality of social relationships has been measured in terms of social intimacy (Miller & Lefcourt, 1982; Robinson, Olmsted, & Garner, 1989), reciprocity (Ingersoll-Dayton, & Antonucci, 1988), confiding (Harrison, Maguire, & Pitceathly, 1995; Primomo, Yates, & Woods, 1990), tie strength (Marsden, & Campbell, 1984), availability of social support (Robinson et al., 1989; Sheffield, Carey, Patenaude, & Lambert, 1995), and quality of personal relationships (Pierce, Sarason, Sarason, Solky-Butzel, & Nagle, 1997). Correlational studies have consistently shown a significant relationship between positive, close and emotionally sustaining relationships, and high levels of psychological adjustment as measured by levels of emotional distress, depression, mood disturbance, self-rated recovery, and loneliness (Blazer, 1982; Miller & Lefcourt, 1983; Pierce et al., 1991; Pierce et al., 1997; Ullman, 1996; Umberson, Chen, House, Hopkins, & Slaten, 1996). Moreover, the quality of the marital relationship has been found to be significantly related to measures of home life satisfaction, mental health, happiness, and overall life satisfaction (Gove, Hughes, & Style, 1983) and to make a unique contribution to a person's mental health after undesirable life events (Lieberman, 1982; Thoits, 1982). These results support the importance of close social relationships in a person's life and in adjusting to stressful life situations.

In the trauma literature, the quality of the social relationship has been measured in terms of the presence of a confiding relationship, and the presence of an intimate and reciprocal relationship (Harvey, Orbuch, Chwalisz, & Garwood, 1991; Kelly,

Coenen, & Johnston, 1995; Pennebaker & O'Heeron, 1984; Pennebaker, Kiecolt-Glaser, & Glaser, 1988; Pennebaker & Susman, 1988; Pennebaker, Barger, & Tiebout, 1989; Petrie, Booth, Pennebaker, Davidson, & Thomas, 1995; Silver et al., 1983; Sorenson, Russell, Harkness, & Harvey, 1993). These studies have included traumatic events such as surviving the holocaust, incest, sexual assault, criminal activities, interpersonal conflict, divorce, abortion, unwanted pregnancy, suicide, and death of a loved one.

A number of experimental studies found that disclosure during the early post-trauma period was associated with increased scores on measures of emotional distress, negative mood, anxiety, intrusion, and avoidance reactions (Gidron, Peri, Connolly, & Shalev, 1996; Pennebaker & Beall, 1986; Pennebaker et al., 1988). However, cross-sectional data suggests that having a close and confiding relationship early during the post-trauma period was significantly related to low levels of negative emotional state, low levels of intrusive memories, low levels of mood disturbance, high perceived success of coping, and high rated success of coping by health professionals one year after the trauma event (Harvey et al., 1991; Miller & Lefcourt, 1983; Orbuch, Harvey, Davis, & Merbach, 1994). Furthermore, women who reported having a supportive confiding relationship during the first month after a rape were found to have lower levels of emotional distress and fewer intrusive memories eight years later compared to women who did not have a confiding relationship early in the post-trauma period, and women who reported negative confidant reactions to their disclosure (Cohen & Roth, 1987). Also important was the finding that women who reported having a confiding relationship following their rape were more likely than those who did not have a confiding relationship to have found a sense of meaning in the event (Silver et al., 1983). Together these results suggest that even though confiding in a close other following a traumatic event may be initially distressing for the person, there are long-term benefits for psychological adjustment.

Social Relationships in Families of Traumatized Persons

Only one family-based study was located that examined the relationship between the quality of a family member's social relationships and their psychological adjustment to a traumatic event affecting a loved one. Cross-sectional data from a longitudinal study (Lepore, Silver, Wortman & Wayment, 1996) has found a significant relationship between the degree to which mothers were able to discuss their infant's sudden death with a confidant within the first three weeks and psychological adjustment as measured by levels of emotional distress from depressive symptoms, and intrusive thoughts. The long-term impact of early disclosure was not reported in this study. A number of studies have examined social relationships in family members of the head-injured.

Social Relationships in Families of the Head-Injured

The potential impact of a head injury on the quality of a family member's social relationships has been measured in terms of leisure activities, activities with the extended family, family stability, family functioning, social functioning, quality of the marital relationship, and parent-child relationships (Hall et al., 1994; Livingston et al., 1985 a, 1985 b; Oddy et al., 1978; Resnick, 1993; Rivara et al., 1992). A retrospective study reported more fighting among family members, less socializing with other family members, a greater tendency to get on each other's nerves, and more family arguments within 8 years post-injury compared to before the injury (Resnick, 1993). Furthermore, difficulties in social adjustment have been shown to be significantly worse for family members of severely head-injured patients compared to family members of mildly head-injured patients (Livingston et al., 1985 a). Other studies have found family members to report higher levels of social isolation and greater deterioration of marital functioning six months following a head injury compared to three months (Livingston et al., 1985 a, 1985 b; Weissman, Prusoff, Thompson, et al., 1978). A problem with these studies is that responses have tended to be grouped without attention to the unique perspective of each family member.

Although no studies were located that examined the quality of the mother's social relationships following the head injury of a child, one study was found that investigated

the social relationships of wives of head-injured patients. A comparative study has shown that one year after their husband's combat injuries, wives of head-injured soldiers were significantly more deserted by old friends, were less close to their in-laws, and were more likely to report their husbands' disability as a social handicap, than wives of paraplegic soldiers, and wives of husbands who had fought in the war but had not sustained injuries (Rosenbaum & Najenson, 1976). Moreover, wives of head-injured soldiers were more likely than wives of paraplegic soldiers and wives of uninjured soldiers to experience high levels of mood disturbance as a result of changes in their social relationships. These results suggest that the quality of a wife's social relationships following her husband's head injury may be important in explaining her psychological adjustment.

Some authors have suggested that head-injured mother's social relationships are not disrupted as much as the social relationship of head-injured patient's wife (Florian et al., 1991; Hall et al., 1994). Only two studies have examined differences in wives' and mothers' social relationships, and these have failed to show significant differences in the social adjustment of wives and mothers of the head-injured (Livingston et al., 1985 a, 1985 b). However, social adjustment was measured in terms of functioning within defined social roles rather than in relation to the quality of their post-trauma social relationships.

Together, these studies suggest a poor understanding of the contributions of social relationships to psychological adjustment of family members to the head injury of a loved one. Furthermore, all of the studies have focused on the long-term impact of the head injury on social functioning and none of the studies have focused on the early post-trauma phase of recovery. A better understanding of the role of social relationships in restoring of a sense of meaning and therefore shaping psychological adjustment during the early post-trauma period may help explain these findings.

Summary

Two variables have received attention in the literature for their potential role in shaping a person's response to a traumatic event. First, the explanations or attributions that a person generates may assist them in restoring a sense of meaning

in their life. However, the research findings have been mixed, which may suggest that attribution-making should be considered as a part of a complex process rather than an isolated entity. A second variable considered important in shaping post-trauma responses is the quality of the person's social relationships. A number of patient-centered studies have shown that close and intimate relationships may enhance a person's psychological adjustment to a traumatic event. In particular, being able to confide in a close other following a traumatic experience appears to have long-term benefits for psychological adjustment. One explanation may be that early disclosure may enhance the search for meaning in the trauma event. However, little is known about how the quality of social relationships fits into this process. Although few family-centered studies have been found in the trauma literature, the evidence so far suggests that the quality of the family member's social relationships is also important to their psychological adjustment. There is therefore a need to examine how the quality of their social relationship relates to the process of responding to traumatic events by restoring a sense of meaning.

Consequences: Indicators of Psychological Adjustment To A Trauma Event

Psychological adjustment can be assessed in terms of affective, cognitive, behavioural, or biological reactions to stressors (Cohen, Kessler, & Gordon, 1995; Lazarus & Folkman, 1984). In the trauma literature, indicators of adjustment have been studied in critically-injured patients (Feinstein & Dolan, 1991; Patterson, Carrigan, Questad, & Robinson, 1990; Shalev et al., 1996), victims of natural disasters (Davidson & Baum, 1986; McFarlane, 1988a), terrorist attacks (Shalev, 1992), criminal assaults (Creamer, Burgess, & Pattison, 1990, 1992), and rape (Silver et al., 1983). These studies have measured psychological adjustment in terms of emotional distress (Davidson & Baum, 1986; McFarlane, 1988; Shalev, 1992), depression (Davidson & Baum, 1986; Shalev et al., 1996; Thompson & Pitts, 1993), anxiety (Grossman, 1995; Shalev et al., 1996), as well as mortality and morbidity rates (MacKenzie et al., 1993; Van Dongen et al., 1993). Psychological adjustment has also been measured in terms of cognitive processing as indicated by the amount of intrusive and avoidant reactions (Creamer et al., 1990, 1992;

Davidson & Baum, 1986; Feinstein & Dolan, 1991), as well as a perceived sense of meaning in the traumatic event (Fife, 1995; Thompson, 1991; Thompson & Pitts, 1993). These reactions have been reported to begin within the first week following a traumatic event (Feinstein & Dolan, 1991; Shalev, 1992; Patterson, Carrigan et al., 1990; Shalev, Schreiber, & Galai, 1993; Shalev, Peri, Cannetti, & Schreiber, 1996) and to endure over the first 12 months or longer (Creamer et al., 1992; Feinstein & Dolan, 1991; McFarlane, 1988; Norris, 1992; Davidson & Baum, 1986; Silver et al., 1983).

Emotional Distress

One frequently used measure of psychological adjustment of traumatized patients is emotional distress. One longitudinal study reported that 63% of patients with multiple trauma had emotional distress as measured by levels of neurotic symptomatology, within one week of the accident (Feinstein & Dolan, 1991). Levels of distress were found to persist over 6 months in 21% of the patients. Furthermore, comparative studies have shown that trauma victims experienced higher levels of emotional distress compared to non-traumatized participants (Creamer et al., 1990, 1992; Davidson & Baum, 1986).

Together, these results suggest a pattern of continued emotional distress over time in a number of trauma victims. However, for many of the participants, these symptoms resolved fairly quickly and for others, levels of emotional distress remained within normal limits during the immediate post-trauma phase. These findings suggest that some people adjust better than others to trauma events. One limitation of these studies however, is that they tended to focus on pathologic rather than health indicators of psychological adjustment.

Cognitive Processing

A person's ability to cognitively process a traumatic event has been conceptualized as a health indicator of psychological adjustment following a traumatic event (Creamer et al., 1990, 1992; Davidson & Baum, 1986; Feinstein & Dolan, 1991; Horowitz, 1986; Janoff-Bulman, 1992; Shalev et al., 1993; Thompson

& Janigian, 1988) and is commonly measured in terms of intrusion and avoidant reactions.

Intrusive memories have been reported as early as the first week after a trauma event (Feinstein & Dolan, 1991; Shalev et al., 1993). Longitudinal studies have shown levels of intrusive memories to remain high in a significant number of victims one week and six weeks after a critical injury (Feinstein & Dolan, 1991) and 4 months, 8 months, and 14 months after a shooting accident (Creamer et al., 1992). In addition, comparative studies have shown the amount of intrusive memories to be significantly higher in traumatized than non-traumatized participants four months following multiple shootings (Creamer et al., 1990) and five years after a nuclear accident (Davidson & Baum, 1986). Similarly, avoidant reactions have been reported as early as the first two weeks after a trauma event (Feinstein & Dolan, 1991; Shalev et al., 1993) and comparative studies have found avoidance reactions to be higher in traumatized victims of multiple shootings four months post-trauma (Creamer et al., 1990) and of a nuclear accident (Davidson & Baum, 1986) compared to non-traumatized victims.

Together, these results suggest a pattern of continued intrusive as well as avoidant reactions during the first year following a traumatic event in a number of trauma victims. As seen with levels of emotional distress, the findings suggest that some people adjust better than others to trauma events.

A Perceived Sense of Meaning

A perceived sense of meaning has been the focus of a growing number of trauma studies. The majority of studies that were located treated measures of meaning as determinants of psychological adjustment. These studies included rape victims and patients with strokes, cancer and chronic illness, and the findings suggest that a perceived sense of meaning was found to be significantly related to low levels of depression, emotional distress, anxiety, pain, and negative moods, fewer intrusive memories, and high levels of psychological adjustment to illness, and a perceived sense of personal control (Barkwell, 1991; Germino, Fife, & Funk, 1995; Lewis, 1989; Thompson, Sobolew-Shubin, Graham, & Janigian, 1989; Silver

et al., 1983). These studies point to the importance of meaning in shaping a person's psychological adjustment to a trauma event.

A perceived sense of meaning may also be conceptualized as an indicator of healthy psychological adjustment (Gottlieb & Rowat, 1987; Janoff-Bulman, 1992; Thompson & Janigian, 1988). Only two studies were located that used a measure of meaning as an indicator of psychological adjustment. A study with 79 cancer patients found that patients were more likely to find meaning if they reported current optimism, low endorsement of irrational beliefs, current internal goals in life, higher level of physical functioning, and low levels of depression (Thompson & Pitts, 1993). Another study with 422 patients at various stages of their cancer trajectory found that patients who were newly diagnosed as having non-metastatic cancer were found to construct a more positive sense of meaning regarding their illness compared to patients experiencing their first recurrence of their cancer, and patients with metastatic cancer (Fife, 1995). In this same study, patients experiencing their first remission were found to construct a more positive sense of meaning regarding their illness compared to individuals experiencing their first recurrence, and those with metastatic disease. These studies suggest a relationship between a person's responses to a trauma event and their ability to find meaning in the event.

Although meaning is a fairly new concept in the trauma literature, the empirical evidence to date suggests its importance in relation to the person's post-trauma reactions and adjustment. The use of meaning as both a determinant and an indicator of psychological adjustment following a trauma event may reflect the need to distinguish the process of finding meaning from the outcome of found meaning. Therefore, examining meaning from a process perspective rather than as isolated determinant or outcome variables may help to clarify these relationships.

Psychological Adjustment in Families of Traumatized Persons

Only a few family-based studies have examined the psychological outcomes of a traumatic event. These studies have consisted of family members of war veterans (Maloney, 1988; Solomon, 1988; Verbrosky & Ryan, 1988), parents of a child's

death to Sudden Infant Death Syndrome (Downey et al., 1990) and patients with critical injuries (Cella et al., 1988; Grossman, 1995).

Only two studies were located that used emotional distress as a measure of psychological adjustment in family members with a traumatized relative. Both of these studies studied parents who had lost a child to Sudden Infant Death Syndrome and found high levels of emotional distress 3 weeks, 3 months, and 18 months after the death (Downey et al., 1990; Lepore et al., 1996). However, they also found the parent's distress scores to decrease significantly over this same time period. These findings suggest that most of the participants adjusted over time.

Current thinking is that like the patient, family members also cognitively process traumatic experiences (Figley, 1995; Janoff-Bulman, 1989). However, cognitive processing has been rarely assessed in family members of trauma patients. The findings of one longitudinal study (Cella et al., 1988) showed that within the first three days of a relative's burn injuries, 52% of family members reported high levels of intrusive memories (Horowitz, Wilner, & Alvarez, 1979). Levels of intrusive memories were found to decrease significantly during the first six months. A similar pattern was noted in their use of avoidance reactions. Together, these results demonstrate that the pattern of intrusion and avoidance reactions after a relative's critical injuries is similar to the pattern found in traumatized individuals.

Only three studies were found that used a measure of a perceived sense of meaning with family members following a relative's traumatic experience (Garamino, Fife, & Funk, 1995; Thompson, Bundek, & Sobolew-Shubin, 1990; Thompson, 1991). Two of these studies used measures of meaning as a determinant of psychological adjustment. Like studies of the traumatized patient, a perceived sense of meaning was found to be significantly associated with low levels of depression in caregivers of stroke patients, 95% of whom were family members (Thompson et al., 1990). A perceived sense of meaning was also significantly associated with low levels of anxiety and depression in partners of cancer patients (Germino et al., 1995). Only one study (Thompson, 1991) was located that used a measure of meaning as an indicator of psychological adjustment with family members. However, since depression and a perceived sense of meaning were highly intercorrelated in this sample and the measures were standardized and summed

(after reversing the direction of the depression scores) to create a single indicator of psychological adjustment. Therefore the study findings as they relate to a perceived sense of meaning specifically cannot be reported. The findings of these studies therefore call for the need to distinguish the process of finding meaning from the outcome of found meaning.

Psychological Adjustment in Families of the Head-Injured

A relative's head injury has been found to have adverse effects on the psychological adjustment of family members. Psychological adjustment in relatives of the head-injured has been studied in terms of perceived burden, psychiatric distress, depression, and anxiety in cross-sectional and longitudinal studies (Hall et al., 1994; Livingston et al., 1985 a, 1985 b; Mintz, Van Horne, & Levine, 1995; Orsillo, McCaffrey, & Fisher, 1993). Studies have shown a pattern of poor psychological adjustment as indicated by high levels of depression, anxiety, participant burden in family members of the head-injured, beginning within one month of their relative's injury. Similarly, 76% of family members were found to report high levels of emotional distress six months after the injury (Livingston et. al, 1985 b). Furthermore, a comparative study has shown that family members of patients with a severe head injury were significantly more emotionally distressed than family members of patients with a mild head injury, (Livingston et al., 1985 a). The findings from these studies indicate that family members of head-injured patients experience high levels of emotional distress. A problem with these studies is that responses have tended to be grouped without attention to the unique perspective of each family member.

A few studies have examined the psychological adjustment of mothers and wives specifically. Two studies were located that examined mothers' psychological adjustment following their child's head injury (Livingston et al., 1985 a; Rivara et al., 1992). In these studies, psychological adjustment was measured in terms of levels of well being and anxiety, and the results suggest that mothers experience significantly lower levels of psychological well-being 3 months and 12 months after the accident compared to pre-injury levels. This was especially true for mothers of severely head-injured adult sons compared to mothers of mildly head-injured adult sons.

A greater number of studies have focused on the wife of the head-injured patient. The psychological adjustment of wives has been measured in terms of levels of perceived burden, emotional distress, anxiety, depression, negative mood, self-esteem, psychosis, and irritability (Hammel, 1994; Kravetz et al., 1995; Livingston et al., 1985 a; Rosenbaum & Najenson, 1976). Results have shown that wives of the head-injured patient tended to report higher levels of anxiety, low mood, low self-esteem, more psychosis, and irritability compared to wives of men with spinal cord injuries, and men without injuries (Hammell, 1994; Kravetz et al., 1995; Rosenbaum & Najenson, 1976). As found in the studies that have included mothers of the head-injured, wives of the severely injured were more likely than wives of the mildly injured to report high levels of emotional distress. Together these studies suggest that both mothers and wives experience high levels of emotional distress following their loved one's head injury.

A small group of comparative studies have examined the psychological adjustment of parents and spouses of the head-injured as measured by levels of participant stress, depression, and emotional distress (Gervasio, & Kreutzer, 1997; Hall, et al., 1994; Kreutzer, Gervasio, & Camplair, 1994). However, findings have been mixed. One study showed that spouses were more likely than parents to report high emotional distress, anxiety, and depression 10 to 14 months post injury (Gervasio, & Kreutzer, 1997). In this study, 80% of the parents were mothers, and 75% of spouses were wives. Grouping of responses may have biased the results. In contrast, cross-sectional data in a study of 16 mothers and 22 wives three months after a head injury found no significance on the occurrence of emotional distress (Livingston et al., 1985 a). One problem with this study is that potential differences in levels of emotional distress between mothers and wives may have been obscured by small samples.

Although these studies suggest a pattern of poor long-term psychological outcomes for the family of head-injured patients, and more specifically the mothers and the wives, there is a significant number of family members who appear to adjust well to the trauma event. Little is known about why some family members adjust better than others. In addition, most of the studies have focused on the long-term impact of the head injury and little is known about the early post-trauma phase of recovery. No studies with family

members of the head-injured were found that included measures of cognitive processing and perceived sense of meaning. A better understanding of the process that restores a sense of meaning and therefore shapes psychological adjustment during the early post-trauma period may help explain these findings.

Summary

A number of indicators have been used to measure a person's psychological adjustment following a traumatic event. The most frequently used indicators have been measures of emotional distress. Patient and family based studies have shown an initial pattern of pathological responses that decrease over time for the majority of participants. However, these measures are construed as pathological indicators and recent studies have begun to examine consequences of trauma events from a health perspective as well. Among these health indicators are measures of cognitive processing and meaning. A person's ability to cognitively process the trauma event and find meaning has been associated with good long-term psychological outcomes. However, little is known about why some people adjust better than others to a trauma event. One recent area of inquiry suggests that the process of finding meaning in the event may hold the key to understanding these findings. Given the findings that meaning may act as both a determinant and as an indicator of adjustment, there is a need to consider the process in its entirety and to distinguish between the process of finding meaning and found meaning. These findings support the need to use grounded theory methodology to uncover the basic social process of finding meaning during the early post-trauma phase of recovery following a head injury.

Review of the literature: Summary and methodological implications

Using the elements (conditions, psychological responses, and consequences) of a paradigm (Strauss & Corbin, 1998) as an organizing framework, this review has highlighted the empirical evidence related to the psychological adjustment of patients and their family members following a traumatic event. Structures or conditions that set the stage for a person's responses to a traumatic event were

reviewed, variables associated with the process of adjusting and finding meaning in a trauma event were identified, and the consequences most commonly measured in trauma studies were discussed. Of relevance to the present study are the following findings.

First, a critical injury such as a head injury is a traumatic event that is characterized by causal, intervening, and contextual conditions. These conditions may vary across situations, and may in part depend on the family member's unique perspective. A small number of studies have found spouses of the head-injured to experience different contextual conditions compared to parents. There is a need to better understand how conditions shape the person's responses to a trauma event.

Second, more attention needs to be given to how people respond to trauma situations. Two variables have been identified as important to the process of psychological adjustment and therefore to the person's ability to find meaning in the traumatic event. These are the attributions that a person makes following the event and the quality of his or her social relationships. There is evidence that attributions may play a key role in helping to create a meaningful context for the interpretation of a trauma event. However, findings have been inconsistent in the types of attribution generated and their dimensions have been found to depend on the characteristics of the specific trauma situation. Moreover, although family members have been found to make attributions following the traumatic injury of a family member, very few family-based studies have examined the role of attributions in the adjustment process. Although a decade of research has not provided conclusive results or direction for practice, it should not be abandoned. Rather, there is a need to examine the construct from a different perspective. The variability in the types of attributions generated and its sensitivity to the conditions surrounding the specific trauma event suggest that attributional activities may be part of a multi-dimensional process of psychological adjustment.

The attributions that people make are thought to take place within the context of the person's social relationships. Empirical findings show that having a confidant significantly reduces the effects of the trauma experience on psychological outcomes. However, trauma studies have tended to measure the presence or

absence of a confiding relationship without assessing the quality of this relationship. Moreover, few studies have examined the quality of the social relationship in family members. Although studies have reported disruption in the family's social relationships following a head injury, particularly for the mother and the wife of the head-injured patient, the quality of social relationships has not been considered as a component of a multi-dimensional process of psychological adjustment.

Third, although pathological outcomes as well as health indicators have been used in the trauma literature, the focus has been on pathological indicators of adjustment. Lacking, also, is an exploration of cognitive processing and sense of meaning in relation to attributions and social relationships in both patient- and family-based studies. There is a need to further explore pathological and health indicators as they relate to the structures and processes of psychological adjustment post-trauma.

Finally, the literature review uncovered three major methodological concerns that needed to be addressed by the current study. One major gap in both the general trauma and head injury literature pertained to the temporal course of post-trauma adjustment. Although the "acute" and "chronic" phases of a stressor event are viewed as conceptually distinct (Cohen et al., 1995), and the length of time associated with each phase may be a function of individual differences and type of trauma, little attention has been given to identifying the subtle differences in structure, process, and outcomes over time. In fact, very little is known about the acute phase of a stressor event such as a traumatic injury and studies have tended to group data from time periods ranging from one to ten years post-trauma. Therefore, the timing for the study was based on several findings in the literature. First, a few family-based studies have shown that family members experience high levels of emotional distress, depression, anxiety, intrusive memories, and avoidance reactions during the first three weeks of their relative's trauma (Cella et al., 1988; Lepore et al., 1996; Kosciulek, 1994; Mathis, 1984). Together these findings suggest a need to further explore the reactions during the acute phase of a trauma event.

A second consideration was based on thinking that attributions may be most important during the early period following a traumatic event (Harvey & Weary,

1984; Wong & Weiner, 1981). A number of studies have found a decrease over time in the participants' concern with making attributions (Downey et al., 1990; Lowery et al., 1989). Furthermore, a number of studies have shown that having close and intimate relationships with others during the first three weeks following a trauma event fostered the disclosure of trauma related thoughts and feelings, and lowered levels of emotional distress over time (Cohen & Roth, 1987; Harvey et al., 1991; Lepore et al., 1996; Orbuch et al., 1994).

A final consideration was that the post-trauma reactions identified in the literature, and their timing, resembled those that characterize Acute Stress Disorder (ASD) and Post-Traumatic Stress Disorder (PTSD) (American Psychiatric Association, 1994; Koopman, Classen, Cardena, & Spiegel, 1995). The diagnostic period for Acute Stress Disorder (ASD) is within the first four weeks following a traumatic event (Koopman et al., 1995), and Post-Traumatic Stress Disorder (PTSD) is diagnosed from 4 to 12 weeks following trauma (American Psychiatric Association, 1994). Given that ASD is thought to be a precursor to the development of PTSD (Koopman et al., 1995), and that family members of the head-injured continue to experience high levels of emotional distress as long as 24 months after their relative's injury (Hall et al., 1994; Livingston et al., 1985; Oddy et al., 1978), a thorough examination of these post-trauma reactions during the first two months after their relative's head injury was needed.

The second methodological concern identified in the trauma literature was that a person's role in the family may influence their perception of the event. Notwithstanding a recent trend in the literature toward measuring the family as a unit (Feetham, 1990; Gillis, 1983; Uphold & Strickland, 1989; Woods & Lewis, 1992), the study of individual family members is recognized to be a crucial aspect of family studies because a person's reactions to a stressor may depend in part on his or her different roles and responsibilities as a family member (Robinson, 1995). In most trauma studies, the family has been assessed in terms of individual members and data from various family members have tended to be pooled without careful attention to the perspective of different family members. Given the variability in contextual conditions, psychological responses and consequences

reported by mothers and wives of the head-injured, there is a need to understand how individual perspectives may influence the person's ability to restore a sense of meaning following a traumatic event.

The third methodological concern was that most of the research has been atheoretical. Furthermore, most of the studies have been correlational and there has been a lack of rigorous qualitative inquiry. These gaps have contributed to a lack of cohesion in empirical findings across studies and, as a result, the findings have had limited clinical utility. Nursing science considers quantitative and qualitative research as complementary and as equally essential to the development of nursing knowledge (Burns & Groves, 1993; Polit & Hungler, 1999). Quantitative research is conducted to describe, examine relationships, and determine causality among variables. It is useful in testing theory. However, in the absence of theoretical understanding, qualitative inquiry is useful in elucidating the multiple dimensions of complicated human phenomena. As such, it is useful in developing theory. Given the state of theory development and knowledge integration in the field of trauma, there was a need for a qualitative study that outlined the structures, processes, and outcomes of adjusting to a traumatic event. Because there has been empirical research done, the study design aimed to bridge research paradigms by building on existing empirical evidence while allowing qualitative data to reveal the multiple dimensions of the human process of living through a traumatic experience.

As a result of the trends and gaps identified in the review of the literature, the current study used grounded theory methodology to further elaborate and refine theoretical understanding of the process of finding meaning after a trauma event, with careful attention given to conditions that defined the trauma event, the participants' psychological responses to the trauma event, and the consequences of their psychological adjustment to the trauma event. Furthermore, the unique perspective of participants and the temporal course of psychological adjustment following a head injury were considered in the study, and mothers and wives were sampled during the early phase of recovery.

CHAPTER 3 - METHOD

Design

Grounded theory methodology was used to further elaborate and refine theoretical understanding of the process of finding meaning during the early phase of recovery following a head injury. Semi-structured interview questions were developed based on variables thought to be associated with finding meaning and provided the initial means of involving mothers and wives in the construction of data about their experience during the early phase of recovery. These questions were intended to provide an initial structure for their stories. Further questions were developed using mothers' and wives' own language to garner additional detail and clarification of their meanings. In addition, they were encouraged to digress in directions of their own choosing and to ignore questions that were not important to their experiences. The goal was to provide structure to verify and elaborate on known variables associated with meaning making while at the same time maximizing each participant's control over her own story. Standardized instruments were also used as a source of data to further describe, explain, and validate emerging themes. Whether information was reduced to words or to numbers, the human experience was emphasized in the collection and interpretation of data. Triangulation across data sources (mothers and wives), time (2-4 weeks and 6-8 weeks following the accident), data collection techniques (interviews, self-report questionnaires), analysis techniques (qualitative and quantitative), and theory, was built into the study design and aimed to foster a more complete description of the emerging process (Lincoln & Guba, 1985).

Study Population

The target population for this study was the wife and/or the mother of a patient who had sustained a moderate or severe head injury. Wives and mothers were sampled because women typically assume the caregiving role following a head injury (Gervasio & Kreutzer, 1997; Hall et al., 1994; Livingston et al., 1985) and consequently, they may be at potential risk for developing psychological problems

following their relative's head injury (Hall et al., 1994; Hammell, 1994; Kravetz et al., 1995; Livingston et al., 1985 a, 1985 b; Oddy et al., 1978; Rivara et al., 1992; Rosenbaum & Najenson, 1976). A moderate head injury was defined by a Glasgow Coma Score (GCS) of 9 to 12 within 8 hours of admission to the emergency room and not induced by medications, and a severe head injury was defined by a GCS of 3 to 8 within 8 hours of admission to the emergency room and not induced by medications. A head injury with a GCS of 13-15 on admission with a positive scan for cerebral pathology within 24-36 hours of admission was also considered a moderate case. Intubated patients with a positive CT scan for pathology were included regardless of GCS. For descriptive purposes, the available GCS was recorded, from the scene of the accident, on intubation or on extubation.

Mothers' and wives' eligibility for the study was determined by the following criteria: a) mother by blood or law, and wife by marriage or law of a patient admitted within the previous 4 weeks with a diagnosis of moderate or severe head injury (based on GCS and CT scan findings in the first 36 hours following admission) at the Vancouver Hospital and Health Sciences Centre and at the Ottawa Hospital (the distance between these sites is due to the researcher's move from Ottawa to Vancouver Island); b) was 18 years of age or older; c) agreed to participate in the project; d) understood and read English; and e) lived within 50 km from the suburb of Greater Vancouver (participants who reside on Vancouver Island were included) or Greater Ottawa. Wives and mothers of patients with a psychiatric or criminal history were excluded. Finally, in the event that the patient's condition was to deteriorate after the first data collection point, as perceived by the participant, time two data collection did not proceed unless the participant said she wanted to continue her participation in the study.

The Vancouver and Health Sciences Centre is the designated Trauma Level I centre for British Columbia and has a full range of neurological and neurosurgical services with a 10 bed neuro ICU, a 60-bed Neurosurgical unit and a 20 bed Trauma ICU. Similarly, the Ottawa Hospital is the designated Trauma Level I centre for Eastern Ontario. Neuroscience services are offered at both the General and Civic sites of the Ottawa Hospital. The Civic site has a 35 beds neuroscience unit and a

five-bed neuro step-down unit. The General site has a 36-bed neuroscience unit and an 8-bed neuro step-down unit. Both sites have a trauma ICU. In all centres, patients with isolated head injuries are admitted to the Neuro-ICU unless they require mechanical ventilation or have other traumatic injuries, in which case they are admitted to the Trauma ICU. They are then transferred to the Neuro-ICU and then to the neuroscience unit when their status has stabilized.

All units have flexible visiting hours with family rooms available for family members who wish to stay overnight. Both centres have a philosophy of care that includes the neurologically impaired client's significant others. All of the units employ an all RN staff with ratios of 1:1 or 1:2 in ICU and neuro ICU, and ratios of 1:6 to 1:8 on neurosurgery depending on patient acuity and shift.

Sampling

Within the study population, theoretical sampling was used as feasible to illuminate the process of finding meaning. As information was obtained, participant selection aimed to achieve theoretical completeness (Strauss & Corbin, 1997). Criteria such as anxiety, coping, culture, and socioeconomic status were used to maximize variation as much as possible. The final sample size and composition was determined when data saturation occurred and when no new themes or patterns emerged. Purposive sampling for maximum variation guided sampling decisions. In keeping with previous grounded theory studies with the trauma population during the early phase of recovery period, fourteen participants were sampled before reaching informational redundancy and theoretical completeness (Hupcey, 1998; Hupcey, & Zimmerman, 2000; Jenny & Logan, 1996; Noyes, 1999).

Participants were sampled at two distinct points during the early phase of recovery to foster disclosure of more sensitive information, and to allow for continuous validation of data for its representativeness and fit between coding categories and the data throughout the study (Lincoln & Guba, 1985). More specifically, the first interview took place within the first four weeks after the injury and the second at six to eight weeks after the injury. The timing between the two interviews was based on DSMIV criteria for Acute Stress Disorder (ASD) and Post-

Traumatic Stress Disorder (PTSD) (American Psychiatric Association, 1994; Koopman et al., 1995).

Procedure

Following ethics approval by the University of British Columbia, the Vancouver Health Sciences Centre – Vancouver General Site, the Ottawa Hospital – Civic and General sites (Appendix A), the principal investigator met with clinicians (Patient Service Coordinators in ICU and Neuroscience in Vancouver, and Trauma nurses and research assistant in Ottawa) to provide an orientation to the study and train them in the recruitment protocol to ensure procedural consistency at each site. Clinicians were provided with recruitment logs and instructed to identify and record any problems or variables in the environment that interfered with recruitment and data collection. In addition to the training session, the study protocol was provided in flow diagram format. The research assistant at the Ottawa site was a registered nurse with a master's degree in nursing and experience in acute and critical care nursing. She was included in the training sessions. The principal investigator contacted each site weekly by telephone/email to inquire about recruitment, data collection, and any problems that arose. A weekly log was kept by the principal investigator about any issues that had emerged and how these were dealt with.

The clinicians identified all patients with moderate and severe head injuries who met the inclusion criteria from the trauma registry. The clinicians on each unit handed out a letter of information to the patient's wife and/or mother and obtained their permission for the principal investigator or research assistant to contact them by telephone to explain the study and to ask for their participation in the study (Appendix A). If the potential participant agreed to participate in the study, a meeting time was arranged at a mutually convenient time and place at Vancouver General Hospital or Ottawa Hospital. The principal investigator / research assistant contacted the clinicians once a week to obtain the names and phone numbers of wives and/or mothers who had agreed to be contacted. The investigator also obtained chart information from the collaborating clinicians about dates of admission, medical diagnosis, Glasgow Coma Score on admission (Appendix B). In the event that a family member refused to be contacted, the clinician

communicated the nature of the refusal to the principal investigator if the participant offered a reason.

A written consent (Appendix A) was obtained at the first meeting. The mothers or wives were then asked to complete a demographic questionnaire and reliable and validated measures of psychological adjustment (Global Symptoms Inventory, Derogatis, 1993; Impact of Event Scale, Horowitz et al., 1979; Meaningfulness in Life Test; Thompson, 1991) (Appendix B). The principal investigator/research assistant clarified questionnaire items as needed and ensured that items not answered or miscoded were corrected if the participant wished to answer the item. The paper and pencil self-report questionnaires were administered first for their evocative qualities and took an estimated 15 minutes. The questionnaires were followed by a semi-structured interview with open-ended questions based on variables thought to be associated with meaning making. These questions provided an initial stimulus for further exploration of the process of finding meaning after a head injury. These questions were sent electronically to the research assistant in Ottawa and discussed in a phone conference. The interviews were audio taped to ensure that all data were captured, and took approximately 60-90 minutes.

At the end of the first interview, the principal investigator/research assistant made an appointment for the second interview to take place six to eight weeks after the patient's accidental injury. The participant's home and work telephone numbers, and her address were obtained, and she was reached by telephone one week before the second session to confirm the date and meeting place. Mothers and wives of patients who were discharged from hospital were interviewed at a location of their choice such as the home or hospital. When a participant refused to commit to the second session, the principal investigator/research assistant recorded the nature of the withdrawal if shared by the participant. At the time of the second interview, the paper and pencil measures of psychological adjustment were completed again, along with some of the initial demographic questions. A semi-structured interview was conducted, with the interview questions modified to validate emerging interpretation of the data and to elicit further theoretical

clarification. The new questions were sent electronically and discussed in a phone conference with the research assistant in Ottawa. Each session took approximately 60-90 minutes.

To ensure the credibility of the findings (Lincoln & Guba, 1985), the principal investigator listened to each tape within 24 hours, made notes, and wrote theoretical and process memos. The Ottawa tapes were mailed to the principal investigator within 72 hours, were reviewed within 24 hours of receipt, and then transcribed. After the transcripts were prepared, the principal investigator listened to the tape again with further note taking and memoeing, and to ensure transcript accuracy. A list was kept of potential participants who were not willing to participate or withdrew from the study, and the reason(s). The consistency in the data was maintained through process memos, which recorded sources of intentional variability (due to the use of constant comparative analysis and theoretical sampling), and unintentional variability (due to participant stress and fatigue, interruptions during data collection changes in the participant's and principal investigator's life situation) (Guba, 1981).

Data Collection Methods

The participants were the primary sources of data for this study and the principal investigator the primary instrument. A variety of data collection techniques were used including a semi-structured interview, valid and reliable measures of psychological adjustment, demographic data, and chart data relevant to the inclusion/exclusion criteria for the study. The focus was on open-ended data interview. Data sources were chosen carefully on the basis of their theoretical relevance, psychometric properties, their evocative qualities, and considerations of the time and energy required of the participants since this is a very stressful time in their life. The measures were piloted on a sample of 10 family members of the head-injured prior to the beginning of this study to ensure the clarity of the item statements, and the appropriateness of the time commitment.

Semi-Structured Interview

Interview questions were developed from the literature on variables reported to be associated with the process of finding meaning after a traumatic event. Given that the emergent fit mode of grounded theory methodology was being used for the study (Artinian, 1988; Strauss & Corbin, 1997), these questions provided a starting point for exploring the relevance of the identified variables to the experiences of mothers and wives of the head-injured during the early phase of recovery. As well, these questions provided a starting point to describe the relationship among variables. At the same time, participants needed the freedom to explore their experience freely without the limitations of structured questions to give more depth and breath to emerging theoretical categories. Participants were encouraged to explore other emerging variables. As a result, the substance and direction of each interview varied with the participants' responses.

The initial probing questions for the first interview aimed to clarify the traumatic situation. Participants were asked the following questions: "Tell me about what has happened to your husband/child"; "How are you managing to get through this experience?" Questions were asked to explore attributions of causality, selectivity and responsibility, and how the participants explained the event. They were asked to comment on whether they had asked the following questions and whether they had found an answer: "Why did the accident happen?"; "Why did this accident happen in my life?"; "Why did this accident happen to my son/husband?"; "Who was responsible?" The participants were asked how they explained the event in relation to the theoretical constructs of order and purpose in life. They were asked: "How has this event (e.g. accident) affected your life (probes: goals, hopes)?" "How is your getting through this experience different from other hard times you've had to get through?"; "How has this accident changed how you view your life?" The participant's social relationships were explored in the context of finding meaning in the event. Participants were asked: "How have others close to you helped you in making sense of this event (e.g. accident)?" "In what ways have they not been helpful to you?" "Tell me about any other people that have been helpful or not helpful in your attempts to make sense of this situation"; "Tell me

about your relationship with your husband/child prior to the accident". Experiences of distress and cognitive processing were explored through the following question: "What has life been like for you since your husband's/child's accident?"

The initial probing question for the second interview aimed to get at the participant's perception of their loved one's condition. They were asked: "Tell me about how your husband/child has been doing since we last saw each other". The probing questions used during the first interview were adapted to each participant's situation guided by their responses during the first interview. Questions were also changed to validate theoretical constructs and relationships as they emerged from the data, and to give the participant the opportunity to further elaborate on their story and bring about other related variables.

Four kinds of probes were used to direct the interview. These included probes to elicit information about the timing and details of events, and probes for further explanation and clarification. Silence was used as much as possible to allow the participant full expression before probes were employed. During the interview, the principal investigator/research assistant kept notes on key words and themes that required probing and redirected participants to these topics. The participants were re-directed only after they had finished expressing their thoughts in order to minimize researcher interference with the natural flow of participants' conversation and increase confidence in the truth of the findings (Lincoln & Guba, 1985). As the study proceeded, the interviews became more or less structured depending on the information already collected and the necessity to validate data.

Quantitative Measures of Psychological Adjustment

Psychological adjustment was measured with the Brief Symptoms Inventory (Derogatis 1993), the Impact of Event Scale (Horowitz et al., 1979), and the Meaningfulness in Life Scale (Thompson, 1991) for the purposes of description and validation of interview data. Permission to use the scales was obtained (Appendix B)

Emotional Distress

The widely used Brief Symptoms Inventory (BSI®) is a 53-item self-report version of the SCL-90-R (Derogatis, 1977) which assessed the level of emotional distress in mothers and wives of the head-injured (Appendix B). This scale's best single indicator of the severity and range of participant emotional distress is the Global Severity Index (GSI) in which the items are rated on a 5-point scale between 0, 'not at all' and 4, 'extremely', with higher scores reflecting more emotional distress. A GSI score greater than 63 signified emotional distress. The reliability test-retest correlations at 2 weeks were reported as 0.68 to 0.91, with internal consistency alpha coefficients of 0.71 to 0.85 (Derogatis, 1993). Sensitivity of the scale has been found to range from 80% to 84 % with a specificity of 87% (Derogatis, 1993). Convergent validity of the BSI® was determined using the clinical scales of the (Minnesota Multiphasic Personality Inventory) with correlations ranging from 0.30 to 0.72 over the nine dimensions of the BSI® (Derogatis & Melisaratos, 1983).

The BSI® has been used extensively in trauma research. Target populations have included individuals with medical conditions such as cancer (Stefanek, Derogatis, & Shaw, 1987; Zabora, Smith-Wilson, Fetting, & Enterline, 1990), victims of terrorist attacks (Creamer et al., 1990, 1992), and family members of burn patients (Cella et al., 1988; Shalev, 1992), patients with dementia (Neundorfer, 1991), and deceased patients (Lepore et al., 1996). The BSI® has also been used with parents and spouses of the head-injured (Gervasio & Kreutzer, 1997; Kreutzer et al., 1994).

Cognitive Processing

The Impact of Event Scale (IES) (Horowitz et al., 1979) is a widely used 15-item measure designed to assess current participant distress for any life event (Appendix B). However, it has been suggested that scores on the IES may be better interpreted as indicators of cognitive processing (Creamer et al., 1990; Horowitz, 1986). The IES was therefore be used to measure cognitive processing efforts in mothers and wives of the head-injured. The scale is comprised of two sub-scales. The intrusion sub-scale (7 items) measures experiences such as ideas, feelings or bad dreams whereas the avoidance

sub-scale (8 items) measures experiences such as avoidance of certain ideas, feelings and situations. Items on the IES are rated according to how frequently the intrusive and the avoidance reactions occurred ('not at all' to 'often'). The scores are obtained by assigning the weights of 0, 1, 3, and 5 to the frequency categories. Scores on the intrusive subscale range from 0 to 35, and scores on the avoidance subscale range from 0 to 40. For both subscales, higher scores reflect a more negative impact on cognitive processing. A cutoff score of 20 for each subscale has been established (Horowitz et al., 1979; Horowitz, 1986), and was used to determine cognitive processing efforts. The IES has shown very good internal consistency, with coefficients ranging from 0.79 to 0.92, with an average of 0.86 for the intrusive sub-scale and 0.90 for the avoidance sub-scale (Zilberg, Weiss, & Horowitz, 1982). The test-retest reliabilities at one week were reported to be 0.87 for the total IES, 0.89 for the intrusion sub-scale, and 0.79 for the avoidance sub-scale (Horowitz et al., 1979). Scores on the IES were found to be predictive of psychological outcome at 6 months with a 100% sensitivity and 97.5% specificity in a prospective longitudinal study of 48 participants admitted to hospital with physical trauma (Feinstein & Dolan, 1991). Furthermore, the IES has been sensitive to change in studies utilizing repeated measurements over time (Cella et al., 1988; Creamer et al., 1990, 1992; Feinstein & Dolan, 1991; Shalev, 1992; Zilberg et al., 1982).

The IES has been used extensively in trauma research. Target populations have included victims of natural and man-made disasters (Davidson & Baum, 1986), criminal assaults (Creamer et al., 1990, 1992; Shalev, 1992), and accidents (Feinstein & Dolan, 1991). The IES has also been used with family members of burn patients (Cella et al., 1988) and HIV/AIDS patients (Pomeroy, Rubin, & Walker, 1995).

Sense of Meaning

The Meaningfulness in Life scale (MLS) (Thompson, 1991) was used to assess the perceived sense of meaning (Appendix B). The MLS consists of 11 items rated on a 4-point scale between 'strongly disagree' and 'strongly agree', with higher scores reflecting a higher sense of order, fairness, and purpose in life. The scale's reliability was calculated for a sample of 132 stroke patients (Thompson, 1991). A Cronbach's alpha of

0.78 was reported for the scale. This was thought to be adequate for new scales (Carmines & Zeller, 1979; Zeller & Carmines, 1980; Nunnally, 1978; Streiner & Norman, 1995). Meaningfulness in life has been found to have a significant negative relationship to depression as measured by the Geriatric Depression Scale (Brink, Yesavage, Lum, Heersema, Adey, & Rose, 1982) in stroke patients, $r(40) = -0.61$, $p < .001$, and their caregivers, $r(40) = -0.43$, $p < .003$ (Thompson, Sobolew-Schubin, Graham, & Janigian, 1989; Thompson, 1991). These relationships have been duplicated with the Centre for Epidemiological Studies-Depression Scale (Radloff, 1977), using a sample consisting of 79 cancer patients and their spouses (Thompson & Pitts, 1993), a further indication of the scales' reliability. The β coefficients for meaningfulness in life have been found to be significant for predicting depression 9 months after a stroke for a cohort of patients, $t(38) = -4.71$, $p < .0001$, and caregivers, $t(38) = -2.83$, $p < .007$ (Thompson et al., 1989). This scale is relatively new, not unlike most scales that measure meaning. However, it was chosen on theoretical grounds, and because it has been used with both patients and their family members.

Demographic Data

Demographic data was collected for descriptive purposes (Appendix B). The categories used on the General Social Survey (Statistics Canada, 1996) were used to collect data about employment, income and education. In addition, background information on the wife and mother's age, marital status, household composition, number of dependents, level of education, employment status, income, ethnic, and religious background, circumstances of the accident such as previous admission to hospital for a critical injury, whether someone they knew had died in the accident, whether the participant had been involved in the accident, who was driving if it was a motor vehicle accident, counselling and support group attendance, and medications. Three visual analogue scales measured the extent to which participants felt that the patient's life was threatened, the extent to which the patient's prognosis was uncertain, and the perception of loss and burden.

Information about employment status, religious activities, counselling, medications, and the three visual analogue scales measuring uncertainty of the prognosis, loss and burden was also obtained at the time of the second interview.

Chart Data

Chart information about the head-injured patient's age, medical diagnosis, accident, dates of admission, and Glasgow Coma Score on admission was obtained for descriptive purposes (Appendix B).

Data Analysis and Verification

Data collection, analysis and verification, and the development of theoretical explanations occurred iteratively throughout the study. Analyses emphasized the description of processes involved in finding meaning following a head injury and comparisons of a priori variables and of theoretically derived groups. Descriptive statistics were used to provide summary profiles of participants and their injured family members, and scores on measures of psychological adjustment were used to support and validate the structures and processes emerging from the analysis of the qualitative data when relevant. An independent audit of the principal investigator's decision trail, data collection and analysis techniques was done throughout the study to ensure objectivity during the analysis (Lincoln & Guba, 1985) and interpretational confirmability (Guba, 1981). The principal investigator and her dissertation supervisor exchanged electronic files, discussed decisions, process, analysis, and emerging theoretical categories and relationships via electronic mail and telephone conference throughout the study. In addition, a nurse who worked with acute-care trauma patients reviewed the codes of selected transcripts for their "fit-worked-grabbed" properties (MacDonald & Schreiber, 2001). The ensuing discussion provided validity for the coding procedures.

Analysis of interview data began with data reduction using open coding procedures in which the substance of the interviews was summarized without imposing any theoretical construction on the data (Strauss & Corbin, 1997). During initial coding, the following questions were asked: "What is being said"; "What do

we have here” (process, phenomenon, event); “How could I label these ideas/experiences?” In addition, initial coding involved dividing the data into concepts, categories of concepts, assigning properties to categories, dimensions of properties along a continuum, and breaking properties into dimensions (Strauss & Corbin, 1997). Categories found in open coding were systematically developed and linked with sub-categories to form more precise and complete explanations about the structure and process of the phenomena. Strauss and Corbin (1997) call this process axial coding. Categories were further integrated and refined through selective coding. Central (core) categories were identified. According to Strauss and Corbin, a central category has the power to pull other categories together to form an explanatory whole that can account for considerable variation within categories. This coding evolved into theoretical coding when relationships between substantive codes were discovered and theoretical linkages were made to contain, describe, and explain the data. The principal investigator maintained analytic and process memos throughout the project in order to document changing views of the data as it was collected and coded, and to compile observations on the conduct of the research (Strauss & Corbin, 1997). The analytic memos reflected the principal investigator's ongoing efforts to "theorize" about the data. Process memos described observations about participants' behaviours and interactions and about the principal investigator's own behaviour in interaction with participants. In addition, the principal investigator solicited the research assistant's insight on the participants' behaviours and interactions as well as her own behaviour in interaction with participants. In addition, the principal investigator validated her observations of the interactions between participants and the research assistant based on the tape-recorded interviews. These observations were also recorded in process memos.

The technique of constant comparison (Glazer & Strauss, 1967; Strauss & Corbin, 1990, 1997, 1998) was used to discover the core category that accounted for most of the variation in the data and that integrated the data, codes, and analytic and process memos accumulated during the course of the study. This entailed moving back and forth among data sets to discover patterns and to determine the presence, variation, or absence of patterns. As core categories emerged from the data, they

were compared to the literature and responses to self-report questionnaires for the purpose of clarifying, extending or refuting previously identified theoretical constructs (Artinian, 1988). This process enabled the principal investigator to compare the degree of fit between study findings and other contexts, settings, and groups (Guba, 1981).

Data matrices were employed as conceptual guides to display elements of the emerging theory. The matrix included various combinations of elements of the data collected from all of the techniques described in order to draw and verify conclusions about the data, to verify interpretations of the data, and linking of substantive theoretical categories (Strauss & Corbin, 1997). This diagramming assisted the principal investigator in organizing themes into a systematic, logical, and integrated account of the phenomena, and informed the need for further theoretical sampling and data validation with the participants. To assist with data analysis, a combination of paper and pencil, drawing tools in Microsoft Word and Atlas-Ti version 4.2 (Scientific Software Development, 1997) were used for qualitative data analysis, management, and model building throughout the study.

Applicability and validation of the emerging theory were tested on two occasions. In March 2002, preliminary findings of the study were shared with neuroscience nurses at a chapter meeting of the Canadian Neuroscience Association in Vancouver. Sixteen nurses attended the presentation and actively engaged in a discussion about how the findings matched their experience as clinicians and the implication of the study findings for practice and further research. Participants found the three phases identified in the study as particularly evocative. They confirmed the shift in the family's focus over time, the levels of assessments that emerged, the influence of past trauma and past relationships on how the participants interpreted the significance of the event and of the patient's injuries, as well as the mediating role of support. There was a discussion of nursing care delivery models and system constraints in relation to working with family members.

In April 2002, preliminary findings of the study were shared with nurse educators through a poster presentation at the annual conference of the Collaborative Nursing Program of British Columbia. The principal investigator

discussed study findings with a number of nurse educators whose expertise was in the area of neuroscience nursing. Like the neuroscience group described above, they validated the three phases and the overall process of finding meaning identified in the study. Moreover, the study findings were evocative for one nurse educator whose husband had suffered a head injury three years before. During a discussion of the findings, she burst into tears and said, “This is all so true. I am sorry, this is really hitting me close to home”. She had been particularly disturbed by the lack of attention to her needs and most particularly her needs for information during the various phases of the acute-care period. Although the principal investigator felt sad that the discussion had caused her to experience intrusive memories, her reactions further validated the findings and provided a test of the theory’s “work-fit-and grab” quality (MacDonald & Schreiber, 2001).

Ethical Considerations

Potential participants were informed of the purpose of the study as well as the benefits and risks. The full extent of their participation was described, and their concerns were addressed. Participants were asked to sign a consent form to indicate that they understood fully the purpose of the project and agreed to participate freely and willingly. They were told that there were no immediate benefits for participating and that there could be some discomfort for those who might become emotional or distressed during the completion of the questionnaires and interview. Data collection was interrupted if participants became distressed or tired, and they were offered a referral to a health care professional on the trauma team. A note was made on the participant’s folder as to the reason for interruption, and the time frame for completion of the interview and questionnaires. In addition, if participants expressed distress from negative relationships and guilt, they were offered a referral to a health care professional on the trauma team. Each participant was given a copy of the consent form with the toll-free phone number of the principal investigator.

To address the possibility that participants felt coerced to participate, clinicians involved with recruitment first asked the patient’s wife and/or mother whether they agreed to be contacted by the principal investigator. They were also

told that the investigator was not part of the medical team and that medical treatment would not depend on whether or not they participated. Moreover, should they agree to be contacted and participate they would be free to change their minds without concerns related to the subsequent quality of medical or nursing care.

To address issues of confidentiality, the principal investigator did not have access to the names or telephone numbers of prospective participants until they had agreed to be contacted. The clinician who approached the potential participant was normally involved in the head-injured patient's care. Potential participants were told that their consent form and identifying code would be secured in a locked filing cabinet and that all identifying information would be destroyed by a shredding process no later than five years after the completion of the study. They were also informed that their questionnaires and audiotape would be coded and would not be identifiable by name. In order to ensure confidentiality of the head-injured patient's chart data, the clinicians provided the principal investigator with the needed data. This information was kept in a locked filing cabinet along with the consent form. The principal investigator the only person who would have access to the raw data and the investigator's dissertation committee would only have access to aggregate and transcribed data. To ensure confidentiality during data collection a private setting selected by the participant or a quiet room at the site where the patient was admitted was selected.

After the interviews, participants were informed that a summary of the overall research results would be mailed to them if they were interested. Ethics approval was obtained from the Research Ethics committees at the Vancouver Hospital and Health Sciences Centre - Vancouver General Hospital site, and The University of British Columbia, and from the Ottawa Hospital – Civic and General Campus (Appendix A).

CHAPTER 4 – FINDINGS

This chapter is divided into two main sections. First, the final study sample is described. Second the results of the analyses are presented.

The Sample

A total of 23 potential participants met the inclusion criteria for the study and were approached by clinicians between September 2000 and October 2001. Four mothers and two wives declined to participate because they felt too upset, overwhelmed, or busy. One mother and two wives had agreed to be contacted and did not return calls. The sample consisted of nine mothers and five wives. The first interview took place within the first five weeks following the head injury ($M = 20.6$ days; range: 5 - 32 days). The second interview occurred 6 - 8 weeks following the head injury and 2 to 5 weeks following the first interview ($M = 31.5$ days; range: 18 - 40 days). At the time of the first interview the head-injured patient was usually still in the intensive care or the step-down unit and at the time of the second interview, most of the patients were discharged home. Three mothers and one wife did not complete the second interview. One mother had returned to her home community and sent back questionnaires and written comments, one mother declined a second interview as she was back to work and too busy, one mother could not be located despite a number of messages left on her home voice mail, and one wife declined because she was being admitted for surgery of a newly diagnosed malignancy. Each interview lasted between 60-90 minutes.

Sample Characteristics

Table 1 summarizes the socio-demographic characteristics of the head-injured patients. The patient group consisted of eight head-injured sons and one daughter ranging in age from 17 to 28 years with a mean age of 22.9 years and five husbands, ages 38 to 65 years (mean 51.8 years). The age and gender distribution in the sample is in keeping with national and provincial head injury population demographics. The Glasgow Coma Scores (GCS) ranged from 3-14 on admission to the ER with 7 patients with a moderate head injury and 7 patients with a severe head injury. The types of injuries

included assaults, work-related falls, motor-vehicle accidents including one pedestrian accident, and two accidental falls.

Table 2 summarizes the socio-demographic characteristics of the participants. The women ranged in age between 44 and 66 with a mean age of 52.14. Most of them had completed high school and had 10-24 years of schooling with an average of 15.57 years. The majority of participants were legally married and living with their spouse and dependent children. Most worked full-time or part-time and the median household income ranged between \$50,000 and \$74,000. Five participants stated that they did not belong to a religious group and only five attended church services. With rare exceptions, the participants felt that the patient's life had been threatened by the accidental injury, and most tended to be uncertain rather than certain about the possibility that he or she would recover. Only two participants felt little or no sense of burden, and two did not report a sense of loss as a result of the patient's injury.

Mothers and wives were similar in terms of age, education, numbers of dependents, religiosity, and the degree to which they felt that the patient's life was threatened, their certainty about the patient's recovery, sense of burden and loss. As well, the GCS was similar between mothers' and wives' injured family member. However there were a few key differences worth mentioning. Mothers tended to come from a more varied ethnic background, to have lower household income and more varied employment status. They also tended to be divorced/separated and living in a non-traditional household. This difference may be attributed in part to the inclusion/exclusion criteria where wives who were legally separated and divorced were excluded from the study. Four of nine mothers and two of five wives were above the cutoff score on the BSI® for emotional distress. As well, six mothers and three wives had scores above the cutoff score of 20 on the intrusion sub-scale of the IES, and four mothers and none of the wives reached the cutoff score of 20 on the avoidance sub-scale of the IES at the time of the first interview. Both the mother and wife scores decreased at the time of the second interview with the exception of a mother whose avoidance score increased above the cutoff score, a mother whose intrusion score increased above the cutoff score, and one wife whose intrusion score remained higher than the cutoff score and in fact increased.

Table 1*Head-injured Patient Demographics and Characteristics*

Variable	Mean	Median	Standard Deviation	Range	Frequency
Type of Injury					
Assault:					3
Occupational:					3
MVA					6
Falls					2
Gender					
Male					13
Female					1
Relationship to participant					
Husband					5
Child					
Son					8
Daughter					1
Age (years)	33.21	26	15.69	17-65	
Children	22.89	25	3.91	17-28	
Husband	51.80	53	9.88	38-65	
GCS (admission)					
Moderate					
13-15 (+ CT Scan)					2
9-12					5
Severe					
3-8					7

Note: N = 14

Table 2*Participant Demographics and Characteristics*

Variable	Mean	Median	Standard Deviation	Range	Frequency
Age	52.14	52	5.87	44-66	
Education (yrs)	15.57	15	3.86	10-24	
Marital Status					
Never married (single)					1
Legally married – not separated					8
Separated – still legally married					1
Divorced					4
Employment type					
Full-time					7
Part-time					2
Sick leave					1
Keeping house					1
Retired					2
Other (self-employed)					1
Household income					
< \$10,000					1
\$10,000 - \$19,000					1
\$30,000 - \$49,000					2
\$40,000 - \$49,000					1
\$50,000 - \$74,000					6
\$75,000 - \$99,000					1
> \$100,000					2
Religious affiliation					
Yes					9
No					5
Attend religious services					
Not at all					4
Rarely					5
Fairly regularly					5

Note: N = 14

Description of the Study Participants

The following is a brief description of each of the study participants. The purpose of this section is to give the reader an understanding of each participant's unique life context, and information about the patient's progress during the acute care phase of recovery. This information is meant to give voice to the participants' experience while preserving confidentiality. Dense background information about the participants, research context, and setting will serve to assist the reader to assess the transferability of the findings (Guba, 1981). Identifying information is not included and the names used are fictitious.

Study participants: wives. A total of five wives participated in the study. Jeanine was a 46-year-old French-Canadian Caucasian woman whose husband was involved in a high-speed single motorcycle accident. His GCS upon admission was 7 and a CT scan revealed right frontal lobe damage with an intra-cerebral hemorrhage distal to the anterior communicating artery vessels with diffuse swelling and a mild right to left shift. At the time of the first interview he had undergone three surgeries and was in critical condition on a ventilator in the ICU. They lived in a small village approximately 10 hours from the hospital where they had been self-employed in commercial fishing. As a result she had to cease work and rent an apartment near the hospital. Jeanine said she was Roman Catholic but rarely attended religious services. She had experienced a number of traumatic experiences in her life prior to her husband's accident, including the death of her younger brother to a head injury, a car accident in which she had been hospitalized, and the death of a friend's family in a car accident. Except for her contacts with the hospital chaplain, she had received no other professional counseling since the accident. Jeanine and her husband had been together for 13 years and they had no children. She described their relationships as close and loving. She admired his love of life and his intellectual capacity. As a couple, they were active in their community and with issues of social justice. They belonged to Amnesty International. Jeanine reported being close to her family and friends and had appreciated their support since the accident. However, the couple's relationship with his family had been strained for a long time. Jeanine described their disapproval of her cultural background and of their chosen lifestyle. As a result, their response to the accident and their presence at the hospital had

been a source of stress for her. A second interview was not scheduled as Jeanine had just been diagnosed with a cervical malignancy and was admitted to hospital for a hysterectomy. Her worries about her husband's condition and about her own health, in addition to being away from home and receiving little support from her in-laws were reflected in a high BSI® score of emotional distress. As well, her cognitive processing efforts were indicated by a maximum score on the intrusive memory subscale of the IES.

Dorothy was a 59-year-old Anglo-Canadian Caucasian woman whose husband had fallen from a 12-foot ladder at work in the construction industry. His GCS upon admission was 14 and a CT scan revealed left frontal-temporal contusions. At the time of the first interview, he had moved from the Neuro-ICU to the step-down unit a few hours before and remained confused and dysphasic. Dorothy and her husband lived within driving distance from the hospital. However, because she did not drive, she had to rely on her sons to drive her. This situation made her feel uncomfortable because she did not like being dependent on others, and especially on her children whom she felt were very busy with young families and work. Dorothy said she had no religious affiliation. The only traumatic event she had experienced was her husband's previous fall from a ladder at work a few years before. He had not been seriously injured at the time. Although she perceived the current injury as somewhat more serious she was confident that he would recover and she reported not feeling distressed about the situation. She had not felt a need for professional counseling and her scores on the BSI® and IES were well below the cutoff score for these scales at the time of both interviews. Dorothy and her husband had been married for 42 years and had two grown children, who no longer lived with them. She was a homemaker and had never worked outside of the home. She liked to read, knit, and enjoyed exploring the Internet. She described her relationship with her husband as close and they spent holidays as a family with their children and grandchildren. Dorothy said that she had received support from neighbours and friends since the accident and that she updated them regularly on her husband's status. At the time of the second interview, her husband had returned home where they awaited rehabilitation services. He continued to be slightly dysphasic and to have periods of confusion.

Cheryl was a 53-year-old Anglo-Canadian Caucasian woman whose husband had also fallen from a ladder at work, hitting his head on concrete. His youngest son who

worked with him on the construction project had found him. His GCS increased from 3 to 6 at the scene of the accident and a CT scan revealed a left communicating subarachnoid and subdural hemorrhage and a right communicating contusion with subdural hemorrhage. He was intubated in the emergency room but did not require surgery. They lived in the suburb of the city and prior to the accident, Cheryl had never driven the car to the city where the hospital was located. In fact, she had been fearful of crossing bridges and tunnels, and as a result, was amazed at her ability to do so following the accident. She worked in an administrative position close to home and her husband was self-employed as a contractor, working with their youngest son. Until the accident, Cheryl had not been involved in the family business. However, following the accident, she worked closely with her son in keeping the business afloat. She worried about the potential financial implications of her husband's accident and how it could impact their son and his partner because they were expecting a child. Cheryl and her husband had a previous car accident where she had been hospitalized for three months due to a fractured pelvis. She said she was Roman Catholic but rarely attended religious services. She had received no professional counseling to deal with emotions and feelings related to her husband's accident. Cheryl and her husband had been married for 34 years and had three sons who no longer lived with them. Two sons lived outside of the province and their youngest son lived within driving distance. Cheryl and her husband had a loving and very close relationship. She considered him to be her "best friend." She said she was close to her children, particularly to her youngest son. She also described a broad support network of neighbours, friends, and co-workers, whom she kept informed through daily updates on her voice-mail system. At the time of the second interview, her husband had returned home where he received Workers Compensation Board-funded rehabilitation services. He continued to be slightly dysphasic, to have periods of confusion, to be emotionally unpredictable and dependent. Cheryl had returned to work on a flexible basis and left her husband at home alone under the watchful eye of neighbours. Their son took over the business with Cheryl's help and frequently brought his father with him to the work sites. Her BSI® score reflected low levels of emotional distress and her IES scores remained well below the cutoff.

Lise was a 53-year-old French-Canadian Caucasian woman whose husband had fallen down the basement stairs following a drinking binge. His GCS was 11 on admission and his CT scan showed contusions and diffuse cerebral edema. He did not require surgery. At the time of the first interview, he had been admitted to the neurosurgical unit and continued to have periods of restlessness and confusion. His memory was impaired and he was dysphasic. Lise and her husband lived in a small town approximately 2 hours from the hospital. Following the accident, she rented a motel room near the hospital and once he was stable, she returned home and traveled to the city a few times a week. She belonged to the United Church and attended religious services fairly regularly. Lise had experienced other traumatic events in her life including her husband's previous alcohol-related motor vehicle accident 5 months before when his license had been suspended and the suicide of their youngest son two years previously. She felt that she had personally come to terms with her son's suicide but that her husband had not. Following their son's traumatic death, he had refused to work with the grief counselor and his alcohol abuse had grown progressively worse. Lise and her husband had been married for 28 years and their relationship had become distant over the years. They had one remaining child, a 29-year-old son who lived with them. However, he was employed and no longer dependent on them financially, and Lise described him as removed from their day-to-day family life spending most of his time with friends. Lise said that her husband had recently retired which had been problematic for their relationship. His alcohol abuse had increased since his retirement and she had been frustrated by his lack of motivation to engage in meaningful activities. She reported having distant relationships with her mother in part because she wanted to shield her from her own marital problems, and the couple was not close to her husband's family who lived in the north of the province. Lise had received no professional counseling to help her deal with her feelings and emotions at the time of the first interview and she was quite distressed by her husband's pattern of destructive behaviour and how it had impacted her life over the years. This was reflected by scores higher than the cutoff on the BSI® and intrusive memory scale of the IES. She had sought professional counseling, but had been placed on a waiting list. At the time of the second interview, her husband had returned home with no plans for rehabilitation. He continued to be

depressed, occasionally searched for his words, had difficulty with complex ideas and tasks, and exhibited dependent behaviours, which frustrated her. Lise had returned to work at the library, in part to get away from her husband. Her scores on the BSI® and IES had returned within normal limits.

Christine was a 48-year-old French-Canadian Caucasian woman whose husband fell at work. His GCS upon admission was 3 and his CT showed a skull fracture with severe fronto-temporal contusions and diffuse cerebral edema. He was placed on life support and his condition had been classified as critical. At the time of the first interview, physicians had given up hope for a positive outcome and they were pressuring Christine to make the decision to discontinue life support. She was upset that they would give up so quickly on her husband and did not feel ready to make this decision. Although she reported feeling extremely stressed by this situation, her BSI® score remained below the cutoff for this scale. In contrast, her intrusion score was above the cutoff on the IES suggesting active cognitive processing. Christine lived in a city suburb 30 minutes from the hospital and was able to be with her husband every day. She said she was Roman Catholic but rarely attended religious services. Christine did not recall any specific traumatic experiences in her life but had had recent contacts with the health care system when her 18-year-old daughter suffered from clinical depression. She had received no professional counseling at the time of the interview. Christine and her husband had been together for 20 years and had two children who were still in school and living with them: a daughter, 18, and a 16 year-old son. She was a homemaker and worked part-time at the local elementary school while her husband held a full-time military career. She described their relationship as a couple as loving and they were close to their children. She also reported receiving strong support from family and friends and seemed to value her mother-in-law's support more than her mother's. Christine felt that her mother-in-law had been helpful in helping her to make decisions and care for her husband whereas her own mother expected Christine to care for her physically and emotionally. Much to the surprise of the health care staff, her husband had regained consciousness and at the time of the second interview, he had returned home while they awaited access to rehabilitation services. He had regained his motor strength but continued to have difficulties with reading, expressive speech, and short-term memory. She said that that he required 24-

hour supervision because he was often restless and exhibited poor judgment. Her mother-in-law continued to help her care for her husband and she had no plans to return to work in the near future. Her score on the BSI® remained below the cutoff but her intrusion score on the IES remained higher than the cutoff, and in fact increased slightly.

Study participants: mothers. A total of 9 mothers participated in the study. Cathy was a 45-year-old Anglo-Canadian Caucasian single mother of three whose eldest son had been hit by a car and thrown across the windshield while crossing a busy road. He was made to wait for emergency care at the scene by a bystander. Emergency personnel found him sitting at the curb with a GCS of 14. Upon arrival to the Emergency room he was sent for a CT scan, which revealed a right fronto-temporal-parietal epidural hematoma with pneumocephalus overlying a comminuted skull fracture. In the CT room, his level of consciousness deteriorated rapidly and his pupils dilated. He was taken to the operating room (OR) immediately and his GCS was 10 upon return from the OR. Cathy lived in subsidized housing in the city suburbs and she drove to the hospital each day. She said she had no religious affiliation. Cathy had experienced a number of traumatic experiences in her life including the recent death of her father and brother to cancer. She explained that these experiences had been difficult for her but felt that her child's injury had been even more traumatic. At the time of the first interview, she had met with the social worker on a few occasions to share her feelings about her son's accident. Cathy had been divorced from her husband for the last 13 years and lived with her three dependent children, two sons aged 19 and 14, and a daughter aged 7. She had recently found new employment as an administrative assistant with a charitable organization. Cathy described her relationship with her children as close and she felt that they had been her "guardian angels" throughout this traumatic experience. At the same time, she was concerned about their reactions to their brother's injuries and she worked at shielding them from her own emotional distress. Cathy said that she had felt comforted by the outpouring of support from her neighbours and close friends. She was close to her mother who came out from a nearby province to help her care for her children so that she could be with her son at the hospital. Although her ex-husband's family lived in the same city, they had had no contact with her or with the children since her separation from her husband. Furthermore, they were not present at the hospital and obtained information

about her son through her ex-husband. Her scores on the BSI® and IES were well below the cutoff for these scales. At the time of the second interview, her husband had returned to provide assistance and her head-injured son was living with his father and grandparents while attending outpatient rehabilitation. A family decision had been made that it would be in the best interest of her son to move to live with his father in an adjacent province so that she could attend to the needs of her other children. She had strong negative feelings about this decision but felt that in the interest of her son's and other children's well-being, she had no choice. Although her BSI® remained below the cutoff, her level of intrusive memories as measured by the IES was very high, indicating active cognitive processing. Her son exhibited decreased inhibition, restlessness, poor short-term memory, and poor judgment. His motor strength had returned.

Monique was a 53-year-old French-Canadian Caucasian woman whose son had been hit by a bus while cycling to work. His admission GCS upon admission was 10 and CT scan revealed an open head injury with frontal lobe hemorrhage and facial as well as ophthalmic injuries. He was taken to the OR for frontal lobe debridement. At the time of the first interview, her son had moved out of the ICU to the step down-unit, and he was alert and oriented to self and to his family. Monique had recently moved from the northern part of the province to be closer to her children and their family. She lived with her 51-year-old brother who was her dependent, and with one of her girlfriends. Prior to her son's accident, she had been on sick leave from her work as an administrative assistant in a large institution and as a result, her income had been severely reduced. Monique had lived through many traumatic experiences in her life, including physical and emotional abuse by her ex-husband during their marriage and for years following their separation, dysfunctional and violent family relationships with her children (in her view instigated by her ex-husband), a diagnosis of cancer, numerous hospitalizations for surgery, a son with schizophrenia who had recently attacked her physically, and her eldest child's motor vehicle accident. She said that she had been traumatized by these life experiences and that she had not yet resolved the aftermath of these events. She was Roman Catholic, prayed daily and attended religious services fairly regularly. Following her son's accident, her ex-husband returned to take control of his son's care and to launch legal action against the bus company. Monique and her ex-husband had been divorced

for the last 18 years and they continued to have a poor relationship. She visited her son at the hospital daily but was frustrated that her ex-husband controlled her access to their son and never left them alone together. She worked hard at finding times to visit when he would not be there but felt that he did everything that he could to interfere with her relationship with their son. She felt manipulated and controlled by him, and worked at avoiding him. Her emotional distress was reflected by scores well above the cutoff on both the BSI® and IES, including high avoidance and intrusive memory scores. She received no professional counselling following the accident. Although she had agreed to a second interview, she could not be located. Numerous messages were left at her home and she did not return calls.

Gurdeep was a 66-year-old East Indian Canadian woman whose son lost control and rolled his vehicle into a ditch while driving on the highway at night. His GCS upon admission was 8 and a CT scan revealed diffuse cerebral edema with a mild midline shift. In addition he had a pneumothorax and a fractured pelvis. His condition was complicated by pneumonia but at the time of the first interview, he had regained consciousness with relatively few neurological deficits. Gurdeep was a Sikh and attended religious services fairly regularly. She had experienced a number of traumatic events in her life, including immigration and the death of her father to cancer. Gurdeep and her husband had been together for 43 years and they had two grown children: their 28-year-old son who lived with them as a dependent because he had been unemployed, and a 37-year-old daughter who no longer lived with them. She described a close and traditional relationship with her husband and a close relationship with her children. She seemed particularly close and proud of her daughter who practised medicine in England and who flew back to Canada to advocate for her parents and brother during the early post-trauma phase of recovery. Gurdeep had family who lived in the same city and close friends one of whom was their family physician. She said that she had received a lot of support from people close to her. Gurdeep and her husband were retired and lived on their pension and she worried about their financial capacity to care for their son. At the time of the second interview, Gurdeep and her husband had adapted their home to care for their son at home. With the help of their daughter, they had also been able to secure help in the home as their capacity to care for their son physically was limited by their chronic cardiac condition.

Their son was neurologically intact but his ambulation was limited due to his fractures. With the exception of an avoidance score above the cutoff on the IES at the time of the first interview, her scores on the BSI® remained low at both interviews and her IES scores had decreased below the cutoff on both the avoidance and intrusive memory subscales.

Nancy was a 56-year-old Anglo-Canadian Caucasian woman whose daughter lost control of her truck while driving on an icy road and hit another vehicle head-on. Her daughter's husband was a passenger in the vehicle and suffered minor injuries. He administered CPR at the scene of the accident until emergency personnel arrived. Her GCS upon admission was 6 and a CT scan revealed a right subdural hematoma and diffuse cerebral edema with a moderate shift. At the time of the first interview, she had just moved out of the neuro-ICU to the step-down unit where she was restless, confused and inappropriate. Nancy and her husband of 26 years lived in a small community eight hours from the hospital. They had two grown children, a daughter and a son, who both lived in a community one hour away. When they received their son's call with the news of their daughter's accident, they had been on a camping holiday in the United States. They returned as promptly as they could to be with their daughter and lived in their camper in a nearby campground. Nancy said that their trip back had been agonizing and they had been worried about their son who was very distraught by having to handle the medical crisis on his own. Nancy said she had no religious affiliation but described drawing on her inner strength to see her through the experience. She had experienced other traumatic events in her life, including the death of her father and of her first husband from cancer. She and her husband were retired and drawing a good pension. She described a close marital relationship with her husband and strong family relationships with their children. She felt strongly that her family was like none other because they spent a lot of time socializing with their grown children and their partners. Nancy also commented on the unsolicited support that they received from neighbours and friends and how this had made her realize how important they had been in their life. Her score on the BSI® was below the cutoff indicating low levels of emotional distress and her IES scores were below the cutoff as well. At the time of the second interview, her daughter had recently returned to her home and she accessed outpatient rehabilitation

services in her community. She had no residual motor weakness other than a ptosis. She remained confused at times but her ability to care for herself and to comprehend complex concepts had improved. Her concentration span was limited, she remained emotionally labile, and required supervision as her judgment was not always appropriate. At the time of the second interview, the family had accessed professional counselling to assist them in understanding their daughter's condition and how they could help her. Her intrusive memory score on the IES exceeded the cutoff for this subscale which may have been a reflection of her working through feelings about her daughter's deficits and emotional upset in the context of their everyday life. Other scores were well below their respective cutoff.

Marise was a 52-year-old French-Canadian Causasian woman whose son lost control of his car when returning home at night. His GCS on admission was 11 and a CT scan revealed right fronto-temporal contusions and diffuse cerebral edema. At the time of the first interview, her son had moved out of the ICU to the neurosurgical floor. He was alert and oriented but remained flat and inappropriate. His attention span was limited and he exhibited poor judgment. However, his motor function was intact. Marise lived an hour away from the hospital and she said that it was difficult for her to be at the hospital on a regular basis. She was Roman Catholic, but rarely attended religious services. Marise had had no other traumatic experiences in her life, but she had recently separated from her husband of 28 years and now lived alone. She and her husband only had one son, the patient, who was 26 and no longer lived at home. Marise said that she had a close relationship with her son and with her family. However, her family lived six hours away and could not be with her at this time. She was employed as a registered nurse in two part-time positions. She had received no professional counseling at the time of the interview. Marise had initially agreed to a second interview, but when contacted, she said that she did not have the time to drive to the city because it was too far and she was back to work. It was then proposed that the interview could take place at a mutually convenient place in her community. Marise declined to participate in the second interview because she was too busy. Her scores on the BSI® and IES were well below the cutoff and Marise had seemed disengaged and distant in sharing her experience at the time of the first interview.

Beverly was a 49-year-old Cree woman whose son had been assaulted at a party. His GCS on admission was 11 and his CT scan revealed a right subdural hematoma, which was subsequently decompressed surgically. At the time of the first interview, he had moved from the step-down unit to a four-bed ward on the neurosurgical unit. His motor strength was intact but his short-term memory was altered, his affect was flat, and he exhibited poor judgment and slow thinking. Beverly lived near the hospital and visited her son daily throughout his hospitalization. She said she was a Christian, but never attended religious services. Beverly had experienced a number of traumatic events in her life. She had been in and out of counseling over the years and she had been struggling to come to terms with her childhood abuse in residential schools, psychological abuse from her ex-husband, the head injury of her eldest son a few years previously and the difficulties associated with his post-injury behaviours which had recently caused him to be in trouble with the law. Beverly and her husband had been divorced for the last 6 years following a 20-year marriage. She described their relationship as strained because of his need to control her. She did not trust others easily including her own family who were present at the hospital. She said that she felt alone in handling this situation. Beverly lived with her two sons, ages 23 and 27, who were her dependents. Her eldest son had been recently admitted to a detention center for a violent outburst at a party, and Beverly was upset by his lack of self-control. Dealing with her eldest son's behaviour, her youngest son's head injury, and with her own unresolved life traumas proved to be very upsetting for her. Beverly had expressed difficulty compartmentalizing her experience and had felt overwhelmed by the situation. Her score on the BSI® was two fold above the cutoff for this scale, indicating an extremely high level of emotional distress. Likewise, her avoidance and intrusive memory scores on the IES reached the highest score for those subscales. Her relationship with her eldest son had been strained but she enjoyed a close relationship with her younger son who was the patient. Beverly's income was modest as she worked as a clerk. At the time of the second interview, her son had returned home and was awaiting outpatient rehabilitation services. Beverly had returned to work and she worried about her son because he slept his days away and he showed no motivation and interest in resuming his pre-trauma activities. She worried that he was depressed and she felt helpless to help him. She was also angry at the system

for not providing adequate access to rehabilitation services following her son's discharge from the hospital. She had received no professional counseling to help her deal with the recent injury of her son and in fact, did not want to access these services. Her avoidance and intrusive memory scores remained above the cutoff on the IES, although lower than at the time of the first interview. Beverly did not fill out the BSI® as she found the scale difficult to answer.

Carol was a 44-year-old Anglo-Canadian Caucasian woman whose son had been injured at a party when friends placed a bucket over his head and hit the bucket with a piece of wood. His GCS on admission was 14 and the ER had called his home to inform them their son had survived a drug overdose and needed to be picked up. When Carol arrived in the ER, her son had just been intubated and his friends had changed their story to reveal the cause of the injuries. She had not expected to find her son in this condition and when she arrived, he was quickly taken away for a CT scan which revealed a skull fracture with contusions and a right intracerebral hemorrhage. At the time of the first interview, he had moved from the neuro-ICU to a four-bed ward. His motor strength had returned and he paced the halls restlessly. He was periodically confused and his concentration span and short-term memory were impaired. Carol lived in the city and she took a leave from her work as an office manager to be with her son. Other traumatic experiences in her life included a divorce and the death of both of her parents. Religion was not part of her life and she had received no counseling. Carol and her husband had been married for the last seven years and she described their marital relationship as drifting. However, she felt that he had been supportive in helping her to make decisions during the early critical care period. The patient who was 19 years old lived with them and was a dependent. Carol's relationship with her son had been difficult from the time he had been two years old. She described numerous behaviour problems both at home and at school and she said that she had felt alone with few people in her life to help her through these situations with her son. However, she said that her husband had a good relationship with her son. Her score on the BSI® exceeded the cutoff, indicating a high level of emotional distress, and her intrusive memory score on the IES was also above the cutoff indicating active cognitive processing. At the time of the second interview, her son had returned home to await access to rehabilitation services as an outpatient. Carol did

not understand why her son needed rehabilitation and she was frustrated that she could not plan for her son's life until rehabilitation was complete. She had returned to work after making arrangements for neighbours to keep an eye out while her son remained at home alone. His memory and concentration span continued to be limited and his judgment was frequently inappropriate. Although her BSI® score was within normal limits, her avoidance score increased above the cutoff at this time. Moreover, her intrusive memory score decreased but remained high at one point below the cutoff.

Marilyn was a 55-year-old Anglo-Canadian Caucasian woman whose son was assaulted when returning home from a friend's house at night. His GCS on admission was 7 and his CT scan revealed several small shears and a left frontal hemorrhage. At the time of the first interview, he had been moved from the Neuro-ICU to the step-down unit. He had regained consciousness but was confused, dysphasic, and restless. He had right-sided motor weakness. Marilyn lived 30 minutes from the hospital with her two youngest children aged 17 and 19, their seven-year-old dog, and her husband of 26 years. Their eldest son, aged 20, was away at university and their daughter was registered to enter university this coming fall. Marilyn described a close-knit family and a close relationship with her husband. She had married into the Jewish Reform faith and attended religious services fairly regularly. She described strong support from family, friends and neighbours and she kept them informed of the patient's status through daily updates on her voice mail. Marilyn had had a number of traumatic events in her life, including her father's heart disease, her ex-fiancé's death in a car accident, and her close friend's battle with cancer. She was self-employed in the family business and the family earned a good income. At the time of the first interview, she had received counseling from a psychologist to help her deal with her feelings about the accident. At the time of the second interview, her son was due to be transferred to the rehabilitation hospital as an inpatient. He had been home on weekend passes and his condition had improved. His motor strength had returned but he continued to have difficulty with speech, complex sequential tasks, and his concentration span and memory were impaired. Marilyn had not yet returned to work and continued to work with her son daily. Her BSI® score and avoidance score on the IES were below the cutoff for these scales at the time of both interviews. However, her intrusive memory score on the IES was well above the cutoff

at the time of the first interview and although decreased at the time of the second interview, it was at the cutoff point for that subscale.

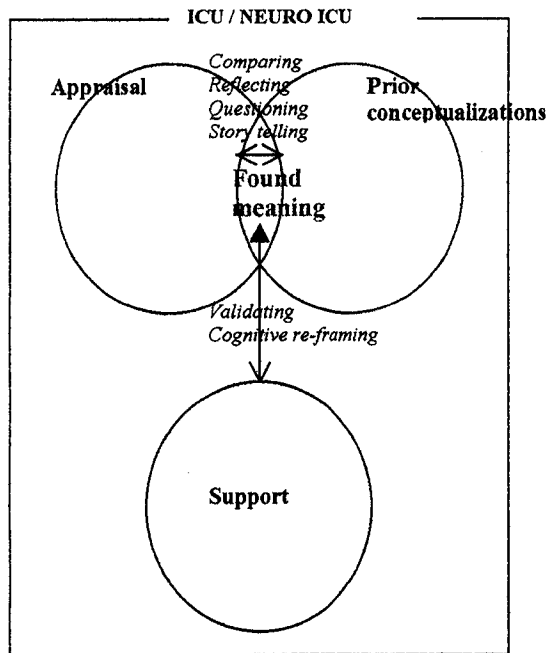
Marg was a 51-year-old Scottish American Caucasian woman who had lived in Canada since she was a young adult. Her son had won a trip to the city with his sports club and their coach had taken them to a city bar to celebrate. She explained that her son left the group looking for a bathroom and bouncers pushed him down the back stairs of the bar on to a concrete landing. His GCS on admission was 5 and his CT scan revealed right acute subdural hematoma, a large left epidural hematoma, swelling and early contusion with a moderate panhemispheric shift. He underwent a right fronto-temporo-parietal craniotomy and evacuation of his subdural hematoma, and a left craniotomy and evacuation of his epidural hematoma. At the time of the first interview, he had been transferred to the step-down unit on the neurosurgical unit. He was awake, alert and oriented, and had regained motor power. His memory and concentration span were altered and he struggled with complex tasks. Marg lived 5 hours away from the city in the interior of the province and had moved in with a friend so that she could be with her son at the hospital. She said she was a member of the United Church and attended religious services fairly regularly. Marg described her experience with other traumatic events in her life, including a divorce, a motor vehicle accident where she was injured, and her son's numerous hospitalizations from age seven to eleven for an autoimmune chronic hepatitis. She and her husband had been divorced for the last 15 years and she lived alone with the patient, a 21-year-old son, who was her dependent. Marg described a close relationship with her son, which she attributed in part to their journey in dealing with his past health challenges. Marg described a difficult relationship with her ex-husband and had needed to see the social worker to have him removed from the hospital. Her upset about the circumstances of her son's accident and her ex-husband's behaviour was reflected in a score almost double of the cutoff on the BSI®. Her avoidance and intrusive memory score on the IES were also well above the cutoff on these subscales indicating active cognitive processing. Marg was close to her family and had received good support from a friend in the city, and friends, neighbours and co-workers in her home community. She was employed full-time as a registered nurse and she held a position on the board of her local school district. Although she had taken a leave of

absence from her work because of her son's accident, she found herself having to go back to her community periodically because of inadequate staffing at her place of employment. This situation frustrated her because she recognized the need in her workplace but found it difficult to concentrate on her work. Marg had agreed to a second interview. However her son was unexpectedly transferred to a rehabilitation center near her hometown rather than to the city facility. Because of the distance involved, a second meeting was not possible.

Figure 1 Overview of Phases

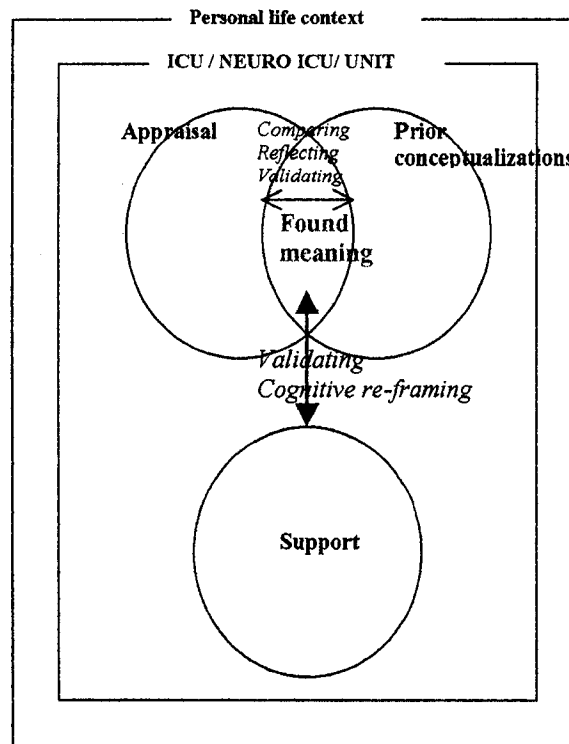
Phase I

Focusing on the Here and Now



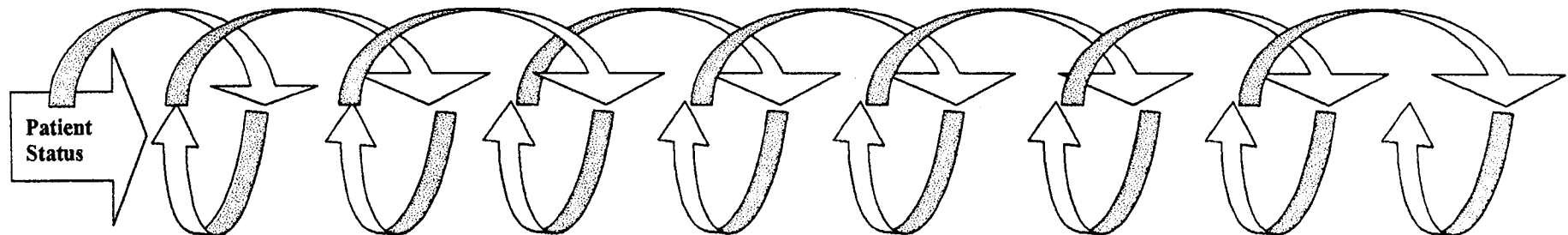
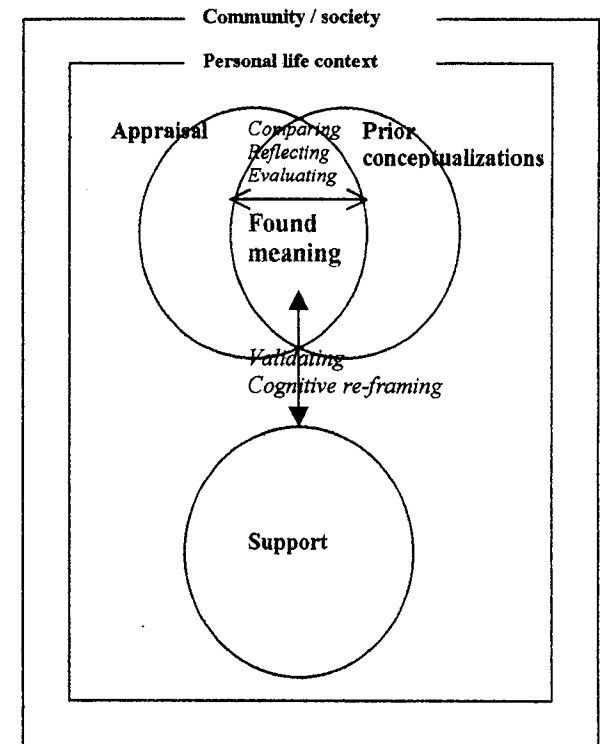
Phase II

Expanding Perspective



Phase III

Resuming life



Results of the Qualitative Data Analysis

As illustrated in Figure 1, three distinct phases were identified during the early phase of recovery: “Focusing on the Here and Now”, “Expanding Perspective”, and “Resuming Life”. Each phase led to the next, based on the participant’s perception of the patient’s status. As such, the trajectory of the process of finding meaning was not linear but rather, journeyed in synchrony over the three phases with fluctuations in the patient’s neurological function. Within each phase, a process of finding meaning evolved that included recurrent core variables. The first was a series of appraisals that participants made and compared to prior cognitive conceptualizations of their life and of the world. As they began to reconcile and find a fit between the current situation and their past experiences, values, and beliefs, they began to restore a sense of stability in their belief system, which continued to evolve across the three phases. As such, their found meaning developed over time. The other core variable that emerged in the data was support. Support contributed to the process of finding meaning in a more indirect manner, depending on the quality of the person’s relationships with others. The extent of contributions from support to the process of finding meaning changed over the course of the three phases. In addition to core variables, a number of basic social process or gerunds (Glaser, 1978) were found to link the core variables. These process variables were a series of strategies such as comparing, questioning, reflecting, story telling, validating, evaluating, and cognitive reframing. Participants used these strategies to facilitate reconciliation of their appraisal of the current situation with prior conceptualizations of their lives and of the world. Over the course of the three phases, core variables and gerunds changed in nature and importance for participants. Finally, the context for the process of finding meaning changed across the three phases. Initially, the participants’ focus had shrunk to the hospital unit. As the patient’s status began to improve the process of finding meaning began to reflect a consideration of what the event meant in the context of their personal lives. As the participants’ focus shifted across the three phases, the process of finding meaning became embedded in their community and societal context.

In the sections that follow, each phase will be described and the core and process variables (gerunds) and their relationships will be examined. In presenting the results,

diagrams representing the overall process for that phase and a series of sub-diagrams will be used to illustrate the results.

Phase I – Focusing on the Here and Now

The onset of this phase began when the participant learned that her loved one had been hurt, usually by receiving a phone call from a relative or from the Emergency Room. Two distinct patterns of reaction characterized this phase. First, the participants experienced cognitive, emotional, and physical reactions. They described an initial period of clarity and action. Marilyn recalls, “I certainly remember being mentally very “sharp” during the early period after the incident.” Over the first few weeks though, participants described becoming increasingly tired and less able to think clearly. They were unable to concentrate on, and take in, new information. Marg illustrated this common experience when she said, “Nothing’s going in and nothing’s sticking there... I almost felt like I had... someone had wrapped my brain in saran wrap.” Participants also described a wide range of emotional reactions such as crying, fear, shock, numbness, sadness, sorrow, stress, anger, lack of anger, relief, feeling sorry, and physical reactions such as shakiness, dizziness, and nervousness, which they tended to attribute to a lack of sleep. Dorothy said, “I think I was more nervous and shaky inside after I knew, he was sort of stable... probably because you know, you’re going, going, going, for hours on end.”

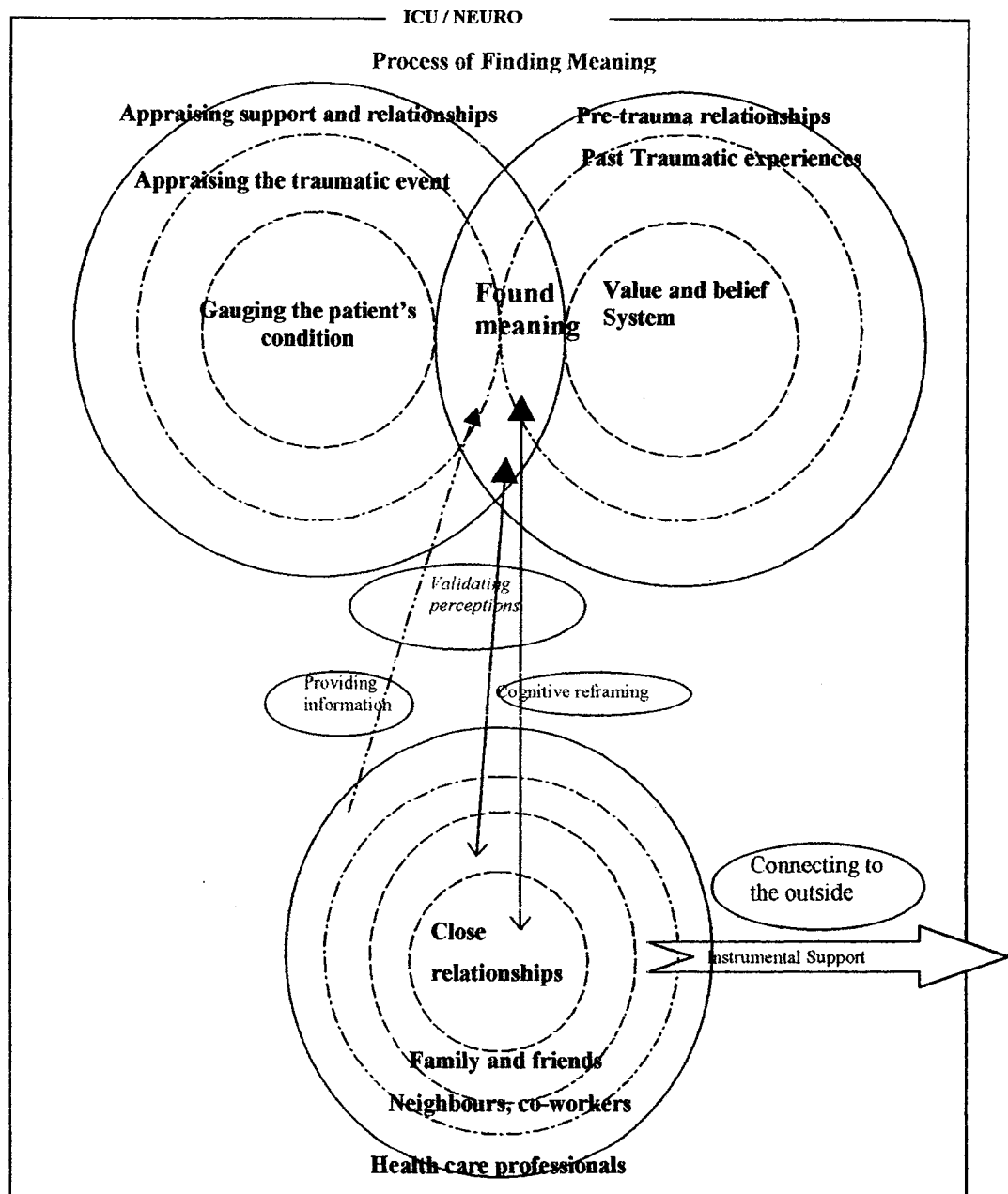
A second pattern of reactions that characterized the initial post-trauma phase was an altered notion of time and a focus on the present. Participants consistently described a blurring of time and place. They commented that time had stopped while the rest of the world was unfolding. They felt disconnected from the context of their lives and of the world. Cathy said, “I feel like it [the trauma] has just happened. It was like nothing else was happening. In the world!” Marg described how she normally organized and planned her time, and how the notion of time had arrested for her: saying, “Your nice little book that you always keep up to date about what you’re doing next, became null and void... It was like there was a wall right here and this is all we were doing, and this hospital was the only important place.” The need to “compartmentalize” the experience by focusing on the “here and now”, seemed adaptive for participants during the initial post-trauma period. Christine explained that she tried to “Cope for the day or maybe, you know, two

or three days at the time” because the future was “too big.” The ability to compartmentalize their experience appeared to enable participants to focus on, and journey with, the patient. It enabled them to adopt a “wait and see” stance rather than to worry about what the possible negative outcomes could be. As Jeanine said, “And my husband was four or five days ago on his death bed... And now they're telling me that he's turning the corner... I operate on a day-to-day basis, and I can't function on reaching so far down the road.”

In contrast, Beverly had difficulty compartmentalizing at the time of the first interview because “everything is coming to me all at once.” Her thoughts about her own childhood abuse and her previous experience with another son with a head injury made her “feel like all of these things are making me spin out of control.” At the time of the second interview, Beverly described how she had eventually learned to compartmentalize during the initial post-trauma period. She said, “Hem, like I'm telling myself now can't think of yesterday, I think of today. I focus now one day at the time... there are times, I still go back there, I'm making myself worse again... I am more focused now.”

Beverly was considerably more anxious at the time of the first interview as compared to the second interview. She cried a lot and her score on the BSI® was 178, which was above the cutoff of 63 on the scale. At the time of the second interview, her BSI® was 38 indicating a marked decrease in her level of emotional distress. This pattern of response was also true for other participants who reported having initial difficulties in focusing on the present. The ability to compartmentalize the experience appeared to enable participants to regain some control and to feel more focused. It also enabled them to focus more intently on the patient. As Cathy explained: “... I'm so focused on just (my son). Like I said, I had blinders on right? ... It was like there was nothing else but him” Being able to focus on the patient seemed critical to the process of finding meaning during this phase. The variables that emerged as central to the search for meaning are presented next. Figure 2 summarizes the variables of importance during this phase, and their relationships.

Figure 2 Phase I – “Focusing on the Here and Now”



Gauging the Patient's Condition

As illustrated on Figure 2, gauging the patient's post-trauma condition was central to the complex post-trauma appraisal process involved in finding meaning following the head injury of a loved one. Although all of the appraisal activities were interrelated, hence the dotted lines between circles on the diagram, the information obtained from observing the patient during this phase was most directly relevant to determining the patient's condition and in evaluating the significance of the traumatic event. The participants' major concern during the initial post-trauma period was whether the patient was going to live or die and as such, they observed the patient intensely for sign of improvement. Furthermore, participants gathered information about the patient's post-trauma status from a number of additional sources such as health care professionals and by observing the reactions of others to the patient's injuries.

Health care professionals provided important information about the circumstances of the trauma event, the extent of the patient's injuries, and the treatment plans and goals. During this post-trauma period, physicians were forthcoming with information about the details of the patient's injuries and their professional opinion about prognosis. Although participants heard this information, they did not give it as much importance as their own observations of the patient's condition and observations of other's reactions, including professionals, to the patient's injuries. The goal of the participants' data collection was to determine if the patient was going to "make it through". In fact, a number of women described having felt very upset by the information that went beyond addressing this most basic concern. Participants were also upset by hearing mixed information about the prognosis that they received from professionals. Cheryl recalled:

When he was lying, there, on the ventilator uh, sedated, so sick, you just wanted him to live, you just wanted him to get better... All, all I wanted him to do was open his eyes and squeeze my hand; I mean that was the level I was at right? ... I can deal with it [information about potential deficits] when it happens if that's what's gonna happen... but not right now when I don't know whether he's going to live or die you know?

Lise recounted the following experience:

The one thing that's been disconcerting is the different messages that you get from staff at the hospital. I realize that they can't predict the future, but like the one doctor, I guess he didn't want me to get my hopes up too much... he was going over ALL of the possibilities, and he was talking about the great rehab unit they have in [town] and I thought, you know? "Come on here, we're not there yet!" and then I'd get really down every time I talked to him. But talking to the nurses, they were much more upbeat and every little advance, you know, they were encouraging.

As illustrated through these examples, participants did not want information about the patient's prognosis at this point and more specifically, information that would indicate a potentially poor outcome. They needed to believe that the patient was going to live. Furthermore, excessive information was contrary to their need to compartmentalize the experience by "focusing on the here and now". Rather, they had a need for information about the patient's injuries, the treatment plans and goals, and ongoing changes in the patient's status.

A major factor in the participants' ability to obtain informational cues from the patient was to be able to physically "be" at the bedside. Nancy's experience illustrates the intensity of observations that occur at the bedside. She said:

What a relief that she's alive! And you can see her, you can touch her, you can hold her, you can talk to her. And when you were talking to her like you could see her heart rate go, so she knew... you knew that she knew you were there.

In addition to being able to gather informational cues about how her daughter was doing, being at the bedside gave her the opportunity to re-connect physically and emotionally with her. The ability to feel a sense of connectedness with the patient gave participants additional information about the patient's status, that is, whether the patient was "there" with them.

As participants made a judgment about the patient's chances of survival they also reflected on the patient's pre-trauma characteristics and identified qualities that would see the patient through. For example, Jeanine said, "He's Mister optimistic. He's Mister positive... so you know what?? This is what's going to get him out of this." Identifying the patient's pre-trauma strengths helped the women believe that the patient was capable

of surviving the injuries. In fact this personal “knowing” of the patient gave them a unique perspective in assessing the patient’s post-trauma condition, and helped them to discount the physician’s negative prognosis and stay focused on possible positive outcomes.

The participants’ observations of the patient’s post-trauma status also initiated a process of reflection about their pre-trauma relationship with the patient. Cheryl stated, [My husband] is my best friend, you know, we spend all our time together... He is such a big part of our life”. In reflecting on the closeness of their prior relationship, participants reaffirmed for themselves the importance of their husband in their lives. Similarly, a mother spoke of how special her son was in her life as well as to others in his life.

Marilyn stated:

He was an inspirational person, almost like a magnet you know? ... But he doesn't just put it out there for his own peers but he puts it out there for almost anybody that he meets. You know, this is going to sound weird, but I think he's got a greater purpose and I don't know if he has to find it through this.

Through these reflections, Marilyn reaffirmed how worthwhile her son was as an individual, which in turn influenced her evaluation of the event. As a result of reflecting on their pre-trauma relationship with the patient, participants also reaffirmed their commitment to supporting the patient. Nancy said: “We’ll do everything that we have to do to get her well again. And nothing else matters”.

In contrast, a difficult pre-trauma relationship with the patient interfered with the participant’s ability to reaffirm the patient’s worth in her life. Lise described having had a poor relationship with her husband who had fallen during a drinking binge. As a result, she was angry with him for messing up her life. She said:

You know, "you screwed up my life, just get your act together you know?" ...

That's a real two-sided thing. I mean I am concerned about him and I want to see him getting better but on the other hand, I'm thinking, "You stupid jerk, you know, when are you going to learn?" (Crying softly).

Because she was so angry and ambivalent, she was having difficulty being supportive of him and to “be” with him at the hospital. She added: “There's only so long you can sit in a hospital and stare at each other (laugh)”. She also had difficulty assessing subtle

changes in his condition.

In summary, participants gauged the patient's post-trauma status by observing the patient and other's reactions to the patient's injuries. Being physically present at the bedside was critical to their ability to make these observations, to connect physically and emotionally with their loved one, and to reaffirm their commitment to the patient. Participants focused their attention on cues supporting their belief that the patient knew they were there and reflected on the patient's pre-trauma qualities. This unique "knowing" of the patient fuelled their belief that the patient could survive his or her injuries and as such, influenced their evaluation of the event. During this phase, information from health care professionals about the event, the patient's injuries and prognosis, treatment plans and goals also contributed to this assessment. However, participants did not want to hear about the physician's assessment of the patient's prognosis, especially if this information predicted a grim outcome. At this point, participants actively focused on information that was positive, which validated a belief that the patient could survive his or her injuries. Furthermore, avoiding information about the patient's prognosis supported her need to "focus on the here and now" and to wait and see if the patient would survive his or her injuries. The quality of the pre-trauma relationship was an important factor in facilitating this process. Participants who did not have a close relationship with the patient had difficulty being at the bedside, and perceiving subtle patient cues. As a result they relied more heavily on information provided by health care professionals. However, as seen with participants who had a close relationship with the patient, they also had a need to believe that the patient could survive his or her injuries, and were quite distraught by negatively biased information. Furthermore, they struggled with reaffirming their commitment to the patient and saw the event as negatively impacting their lives.

Appraising the Traumatic Event

As illustrated in Figure 2, appraising the traumatic event was also part of the complex post-trauma appraisal process involved in finding meaning following the head injury of a loved one. A number of sources of information contributed to their evaluation of the event. Health care professionals and other involved professionals such as

policemen, insurance adjusters, and lawyers provided details about how the event occurred. However, participants' perception of the patient's post-trauma status as well as their judgment of whether the patient was going to survive, were the most important sources of information in evaluating the significance of the event. As participants appraised the event, they used a number of strategies to reconcile the event with their reconstruction of past experiences and their values and beliefs about the benevolence of the world, control, fairness and justice. They used the following strategies simultaneously: comparing, questioning, reflecting, and story telling. For example, participants would ask themselves why an event occurred and proceed to answer their own question by reflecting on what had happened, comparing the event to prior life experiences or drawing from examples in the media. They engaged in these mental processes by sharing their thinking with others, by journaling, or by using self-talk. They worked through these trauma-related thoughts until they found a comfortable fit between the current situation and their prior conceptualization of their world, in the form of an explanation. The use of these strategies was therefore an indication that the participant was actively processing their thoughts and feelings.

Assaults more than any other type of injury in this study seemed to challenge the participants' value and belief system. Marilyn, whose son had been assaulted, spent a lot of cognitive efforts in explaining the event in the context of a community and a society that has failed children such as the perpetrators. In addition to her struggle about the lack of justice in society, she reflected on the fairness of what had happened to her son and to her family. She said:

They knew that a couple of these kids were bad apples in their community and had the opportunity to do something about it and chose not to. They, over time have let things erode their community and now it's eroding outside the community too ... But I say that this is a result of bigger problems in our society you know... I have felt anger towards our justice system or lack of justice system... And sadness about these boys, men, who were raised without compassion for life, and therefore raised without compassion for their own life...

I certainly don't believe that there's anything that he's [my son] done in his life to deserve this, in any of our lives... We like to stay in our little comfort zone, and

yet there is a lot of pain around us... You can't open up the paper without reading about them [child abductions, the mid-east affair]. I think that we, as a society, need to wake up!

This example illustrates how a person's belief system can be shaken at multiple levels. Marilyn's struggle to reconcile the event with her conception of the world speaks to the extent to which her values and beliefs had been undermined, and to the intensity of the emotional and cognitive work required to re-build her values and beliefs about the world as benevolent, just, and fair. She reflected on the situation and on the world in general, she questioned why this had happened, who was responsible, and why it had happened to her son. She also spoke to others about her thoughts and feelings and used a journal to reflect on her thoughts and feelings. In fact, her cognitive work was ongoing at the time of the second interview, which was reflected by her high scores (above the cutoff) on the intrusion sub-scale of the IES.

Other events such as motor vehicle accidents, occupational accidents, and falls seemed to trigger reflections about participants' values and beliefs of control and fairness more specifically. As a result of the traumatic event, participants reflected broadly on whether or not the event could have been avoided or prevented. For example, Jeanine said, "Umm, and I think that it's life, and you can't justify everything about it, it just happens." Dorothy also shared the following thoughts, "Accidents happen you know, that's the problem so. But it, I mean, they wouldn't be called accidents if they weren't, because accidents happen you know, so... there's nothing you can do about it." As a group, their loved one's accident reinforced the belief that overall, one had very little control over the occurrence of traumatic events. They appeared to accept readily that events could happen in life for no reason, or for reasons that they did not know or understand, and would likely never know. However, when participants reflected on their belief about a lack of control in life events in relation to what had happened to their loved one specifically, they seemed troubled by this lack of control and in fact, began to focus on values and beliefs about fairness. For example, Jeanine, whose husband was involved in a motorcycle accident, expended a lot of cognitive energy, struggling back and forth between her perception of why her husband did not deserve to be hurt, how things happened for no reasons in life, and how the world was not fair in the first place. She

recounts:

I mean as freaky as it is... why this happened, and you can't understand it, you think that God cannot be fair, but yes there's other things that are going on in the world that's just not fair... I find that [my husband] was totally undeserving... He's a lovely human being that doesn't ever wish bad on anyone. He's umm, full of life, very sweet, lovely creature. I find that really unfair. Because he's safe. He came back to get his helmet because he forgot it. Umm, [my husband] had the right gear, he was wearing the protective gear, like umm, pants and jacket... And he really valued his life. Really valued his life. He wasn't reckless.

This quote illustrates a circularity of reasoning which attests to the interrelationship of values and beliefs about controllability and fairness, and how traumatic event can undermine this fit. Quantitative data support this in that her score on the intrusion subscale of the IES also exceeded the cutoff of 20, indicating active processing of trauma-related thoughts.

How the event influenced the participants' view of the world also appeared to depend on the person's past life experiences. Most of the participants had lived through previous traumatic events, which they felt had made them stronger in coping with the current crisis. Lise's teenage son committed suicide two years before and the experience had taught her that "conflict is not unusual, it's sort of a typical thing, it's not a bad thing, it's something you have to deal with". Similarly, Nancy said: "I've had other things happen in my life, but when I look back, definitely not as traumatic as having a child injured, but I lost a husband when I was very young. And umm, it makes stronger people out of you" As seen in these examples, previous traumatic events seemed to create room for negative experiences in a person's values and beliefs about the world.

However, what appeared to influence the person's ability to draw strength from her previous traumatic experiences was whether or not these experiences had been resolved. When resolved, the new traumatic event appeared to be integrated into the person's values and beliefs with more ease. In contrast, if previous traumatic events had not been resolved, and particularly if the person had used avoidance behaviours as a coping response, the effect of the new trauma event appeared to be cumulative. Beverly most particularly exhibited this response. She told her story of sexual, physical, and

emotional abuse that began in her early childhood and continued through her relationship with her husband. In addition, her eldest son had suffered a head injury after having been hit by a drunk driver a number of years previous to her current son's head injuries. She described the following thoughts:

I just put the damper on it and things happen to open the pressure cooker again... It should be all gone from my mind you know, but it's still in there you know. And I don't want it to come out... because now it's happened to my youngest one. But I was still trying to push this one aside... And it gets harder and harder over time. It just seems to get stronger and stronger. That's why it's like so upsetting... (Weak voice). No matter how much you say I've dealt with it, it's all gone and then the wound is reopened. So how do you get rid of it? ... With [my eldest son], I was told what to do, where to be by my husband... I never dealt with it you know. I didn't deal with it at all. I let it go by me! I don't remember much, I was numb.

Beverly expressed a lot of pain in her life and throughout the interview, she returned to memories of her past life experiences and expressed how much these continued to trouble her despite attempts to put them out of her mind. She also commented numerous times on how her son's recent accident was adding to her already burdened emotions. In addition, she had difficulty compartmentalizing the experience and as discussed previously, she felt that everything was coming at her all at once, making her "spin out of control". Her high level of emotional distress was also reflected in her scores on the BSI® and IES, which exceeded the cutoff, indicating a high level of emotional distress and intrusive and avoidance reactions.

In summary, as the participants gained information about the event and the patient, their story showed a back and forth process of making sense of the information in light of their past experiences and of their basic values and beliefs about the world. This process resulted in an explanation for the event that tended to be positively biased. Over time, participants' past traumatic experiences appeared to create room for reconciling negative events with their value and belief system. However, when past experiences had not been resolved, and particularly if participants had used avoidance as a coping strategy, they struggled at finding a fit and in fact added to their already burdened

cognitive and emotional load. Another factor in the person's ability to work through the traumatic event was how much it undermined the person's values and beliefs. It seemed that the more disrupted the participants' value and belief system was as a result of their loved one's accident, the more difficult it was for them to find an explanation for the event. The process of reconciling information with their value and belief system continued over time and participants continued to search for possible explanations for the event, frequently manifested by describing many competing explanations. Regardless of the amount of cognitive efforts required in reconciling the event with past experiences and their values and belief system, all participants focused on explanations that had a positive bias. Furthermore, during this phase, participants tended to keep the level of explanation about the event at the broader level of "life" as opposed to "their" lives. This is consistent with their need to compartmentalize their experience at this time and to favour uncertainty about the patient's prognosis.

Appraising Support and Relationships

Another aspect of the appraisal process during the early post-trauma phase was an evaluation of the support that participants received from others (see Figure 2). Participants engaged in a process of comparing current to pre-trauma relationships with others, which influenced their willingness to accept support from others. When support from family, friends, and neighbours was available, and participants felt comfortable accepting it, they were better able to focus on the patient because it enabled them to "be with" the patient and they did not have to worry about keeping life at home and at work afloat. The level of support that they perceived was also compared to their values and beliefs about benevolence of the world around them. This in turn influenced their appraisal of the event, which was particularly significant when their beliefs about other people were shaken, as seen when the traumatic event involved an assault.

Most study participants were thankful for the support that they received from family and friends during the early period following the head injury. They described positive pre-trauma relationships with others in their lives and willingly accepted their assistance. It was important for the family to be at the hospital with them. When asked specifically how others were helpful in helping them cope during this phase, participants

readily identified the instrumental supports that they received from family, friends, neighbours and their community. Cathy described how her own mother took care of her other children so that she could focus on her son and be in the ICU with him. Others described a variety of ways in which close others assisted, such as ensuring that they had rest, food, and even clothing. This help enabled them to be able to have the energy to focus on the patient. Participants also spoke about how friends, co-workers, and neighbours helped them take care of their house, gardens, and work-related duties so that they did not have to worry about taking care of life outside the hospital. Cathy, a single mother, described the following:

I've got some awesome friends. I mean I live in a co-op with 56 units, they're behind me 100%. Anything I need. When I was staying in the ICU, four of my girlfriends went in and cleaned my house from top to bottom, cleaned all my laundry. I mean they've been fabulous!

Jeanine said that finances were a concern because they were seasonal workers in the fishing industry. She told the story of how her community had rallied behind them. She said, "But you know, where we live, there's only like fifteen other people and maybe two thousand total with the major island... and they have been so supportive, they've even had a trust fund for [my husband]." Overall, participants felt that the support that they had received had helped them to take care of life on the outside so they could focus on the patient. Moreover, they felt comforted by close others' presence at the hospital, even though they could not describe specifically how others comforted them.

Although participants recognized the importance of having support they also felt the need to control the flow of support in order to conserve their energy and protect the patient. Cheryl reported saying to her family, "No give me a chance to just try and get myself together... also, I thought nobody should see him like that. You know, if he wakes up, he'll be embarrassed. So I'm keeping that protected". Most participants expressed similar feelings during the early post-trauma period and as a result, many developed strategies to "monitor the traffic" such as putting daily updated messages on the answering machine. In addition, other participants controlled who could visit the patient at the hospital. Jeanine said, "My husband's friends come but they don't know how to help so I send them away. It is easier in some way if they are not around because

I can't take care of them too!" These examples illustrate that even though participants appreciated the support of others during this initial post-trauma phase, their presence could also be a source of stress for them.

A few participants described their pre-trauma relationships with others as difficult, which resulted in battles for control and a difficulty in accepting support from them. Beverly, who had been divorced from her son's father for the last six years, described how he had come to the ICU after her first son's head injury and outlined for nursing staff who could visit his son. She said:

All the names were all there on the list to visit, only I didn't have a space for my name, or my friends or his [my son's] friends, so I was crying there and I was saying I can't believe this... So this time, he came and expected to take over again. I wouldn't let him and he didn't like that.

Moreover, she did not have a close relationship with her own family and felt that they would take control if she accepted their help. Accepting help from others could also be risky if there were issues that the person wanted to hide. For example, Lise told the story about how she had hidden her husband's drinking problem from her mother and others in her life. She said:

She worries about me, that I'll get too tired and how I'll cope with it, but she wasn't even aware of my husband's drinking problem until the accident ... but different values for sure are at play here, as she hardly drinks at all you know? ... And so, over the years, I haven't confided in her about the reality of things. I don't know whether that was a good thing or not but, I felt protective. But I'm getting to the point where I'm trying to use my energies hiding our dirty laundry? ... Like I want people to know what I'm going through so I can get some support for myself (gently crying). But I hate to mess up his life either you know, unnecessarily?

As seen in this example, support was a double-edged sword for Lise. In addition, the couple's relationship with his family was not close. She felt overwhelmed and alone in coping with the situation. In fact, her BSI® and intrusion scores were above the cutoff for those scales indicating a high level of emotional distress and incomplete cognitive processing.

When participants described the support they received from others, they did not readily mention health care professionals as a significant source of support for them, except as a source of informational support. However, when asked probing questions they were able to identify ways in which staff had been supportive and unsupportive. Participants described the following behaviours as supportive: explaining treatments, allowing family members to participate in the patient's care, sharing their perception of the patient, being attentive to their comfort and rest, inquiring in the cafeteria as to how the patient was doing, and helping with paperwork. Although family members did not want information that related to the patient's prognosis, they needed information about treatments and procedures. Knowing that the patient was well cared for and understanding what was going on with the patient was perceived as supportive. Cheryl recalls:

He was so sick in ICU when he was on the ventilator but I found the nurses there were awesome. They explained everything to you, they explained what they were doing, and they explained why they were doing it. I was fine with it.

In contrast, other behaviours were perceived as unsupportive. One example was how personnel had "routinized" their work. Cheryl said:

I found neuro ICU not merely as friendly as ICU? In neuro ICU I thought we were kind of a hindrance. Like really, they would rather we weren't there. Because they get to take it all for granted? And same as when they said, the other night, the night before last, they said you may be moving up to the unit, we're just going to probably keep him here for 24 hours just to check his breathing. I said, "Oh okay", and she said, we're getting five cranies in tonight and this is happening and that's happening, and I said, you know, you guys? This is scary as hell for families. Really! I know it's your job and I know you take it for granted, but my God, don't ever let this happen to you, you know? And I think they have to, because I think their jobs are brutal, don't get me wrong. I can't imagine being a neuro ICU nurse.

Other unsupportive behaviours reported by participants were: never seeing the physician, feeling pressured by physicians in making life and death decisions, and a lack of common courtesy such as acknowledging their presence and introducing themselves. In fact, a

number of participants described how nurses would leave the bedside without talking to them when they arrived to visit the patient. For example, Jeanine said, “I get the feeling that they are trying to avoid me. When I arrive, they leave. They could tell me ‘I’ll leave you with your husband’. Otherwise I think they are trying to avoid me.” Such behaviours were perceived as unsupportive and participants felt that it added to their already high level of stress and that it made it difficult for them to access assistance.

In addition to assessing the support available from health care professionals, participants also assessed their competence. Competence was informed by their perception of the appropriateness of medical/nursing interventions and by the consistency of information provided. Although for the most part, participants described staff competence favourably, they described how they watched and worried about the effect of some of the interventions on the patient. Cheryl gave this example:

We had a couple nurses that would run around to take temperatures and shine a flashlight in his eyes, make him open his eyes, make him move his hands, make him move his arms, and watching them you're exhausted.... I thought, God, this poor man's fallen and what are you doing?”

Participants were also particularly worried by the lack of information about the patient's status by physicians in particular. Jeanine said:

It's all about communication and relationships, being levelled with and not patronized, treated like I have some intelligence. Tell me the little changes or even that there is no change. I need to know to figure out what is going on. If there is no news, I tell myself that something is really wrong.

The distress caused by a lack of information about the patient's condition and progress takes on added dimensions considering that this information contributes to the participant's assessment of the patient's post-trauma status and whether or not the patient could survive his or her injuries. Although participants were upset by a lack of appropriate communication, they offered numerous reasons to explain discrepancies in the patient's care and in the flow of information. Some of these were related to increased workloads, the traumatic nature of working in emergency rooms and ICU's, and the difficulties involved in predicting head injury outcomes.

In addition to appraising health care professionals, participants evaluated various aspects of the health care system. One aspect that was particularly relevant for them related to being able to “be” with the patient in the ICU and neuro ICU. Often, participants were kept away from the bedside because of a concern for the patient’s intra-cranial pressure. Participants recalled becoming quite upset by this separation. They also shared frustration with how visiting hour policies were implemented. Cathy had the following experience:

When he had cranial pressure increase and everything else, for sixteen hours that we could not see him! And that was devastating. She didn't want me in the room, anybody in the room, in case... So they didn't want any increased brain activity right? So, that was just devastating, not being able to touch him, you know? It was like "Oh my God!" you know? It was the worst time!

Cheryl described being kept away because of change of shift practices in the unit. She also commented on inconsistencies with which visiting policies were applied. She shared the following experience:

I just, needed to sit there. I found in ICU there was a couple evenings that I stayed later, once he sort of started moving around, maybe once he opened his eyes a little bit? Um, and they let me stay right through shift change. Cause I didn't think I'm sort of hard to get along... I just, needed to sit there? And so, I thought that on neuro ICU that maybe they could have let me do that.

As these examples illustrate, being kept away from bedside caused participants some distress and interfered with their need to focus on the patient. This takes added importance given that being at the bedside is critical to the family member’s ability to gather informational cues about how the patient is doing and helps them to evaluate the importance of the event.

Another aspect of the health care system evaluated by participants was response time to the patient’s needs for medical attention. They shared being frustrated when the patient had to wait, particularly for diagnostic tests, because departments were too busy. A lack of timely access to services made participants feel unsupported in their need to protect the patient’s best interest. For example, Monique said:

I was very disappointed on Friday that [my son] didn't get his MRI you know? I

can understand about all this [referring to cutbacks] but it's like when it's your son, and you know he has a 24 hour a day almost headache and it won't go away, and what is this blood clot, what does it mean? Is it going to get worse?

In addition to appraising support from others in order to determine whether or not they could accept support, they also compared the level of support they received to their values and beliefs about people as intrinsically well meaning. For example, Marilyn, whose son had been assaulted, commented on the overwhelming support they received from others, including strangers. Even though Marilyn blamed society in general as well as specific individuals for her son's injuries, the outpouring of support particularly from total strangers helped her to evaluate the traumatic event in the context of a world where people are generally benevolent. As such, it helped to re-establish a positive bias in her value and belief system.

In summary, participants appraised the support that they received from family, friends and neighbours, as well as professionals and the health care system. They compared the level of support they received to the quality of their pre-trauma relationships and their expectations for support, which in turn helped them to determine whether they felt comfortable accepting support from others. Assistance from others was important in enabling them to be physically with the patient and therefore to assess and advocate for the patient. Moreover, the instrumental assistance that they received reduced their worries about taking care of life on the outside. However, the outpouring of support was sometimes overwhelming for participants and they used strategies to disseminate information and restrict visits from people who were not as closely linked to their family. Participants' willingness to accept support from others was primarily influenced by the closeness of their pre-trauma relationships. A number of participants who had experienced difficult relationships with close others prior to the accident described the risks inherent in accepting support. They described battles for control about the patient's care and fears of loss of control. They were also concerned about repercussions if they revealed details about themselves and the cause of the accident. Overall, health care professionals were not mentioned as a source of support other than informational support. However, when this was explored further, participants identified ways in which health care professionals had been both supportive and unsupportive,

though they tended to focus on staff behaviours and system issues that interfered with their ability to assess the patient and the event and to advocate for their loved one. One last aspect of appraising support and relationships involved comparing their perception of post-trauma support to their prior conceptualization of the world. As a result of the outpouring of support experienced by participants, most recognized that the world was generally benevolent and this in turn contributed to their assessment of the event.

The role of support in the process of finding meaning. As illustrated in Figure 2, the process of reconciling the appraisal of the support and relationships with pre-trauma relationships and values and beliefs about benevolence of the world resulted in new ways of interpreting the event in the context of life. As such, participants restored a sense of stability in their belief system or found meaning. However, support was also found to play a distinct role in the participant's search for meaning. Although early diagrams had included support as overlapping the process of finding meaning, it became evident that it could both facilitate or hinder the process depending on the quality of the person's relationships with others. Moreover, some of the participants who had difficult relationships with others still managed to reconcile trauma-related thoughts with their pre-trauma values and beliefs. The support circle was therefore moved outward and construed as a mediator of the process of finding meaning.

During the initial post-trauma phase, participants had difficulty describing specifically how others helped them to cope with the event, other than by "being there" and providing instrumental support. The difficulty in articulating how others helped them to come to terms with the event may be related to the fact that there was a greater emphasis on accepting rather than mobilizing support at this time. This is illustrated by the arrows in Figure 2 indicating a stronger direction towards the participant from supportive others. Marilyn illustrated these dynamics when she said:

People ask me "how can I help you", and the hard thing is that you get to the point where you say "I don't know what you can do". Because I haven't got my life in order? And so I don't know what you can do you know? ... And then I think there's some people, and I fit in this category, who find it difficult to ask people to do things for them. I like being independent, you know? ... And I have chosen this time, to let people help me out.

Although participants were unable to say how others could help them at this time, and more specifically how they could help them to make sense of the situation, embedded in a number of participants' stories was evidence that others played a role in validating their perceptions of the event and of the patient's status. Lise recalled:

Well I haven't talked to a lot of different people but to one person in particular, has been very supportive, came in with me one day and hem, just even having a friend who has been in here and has seen him and so, knows what I'm talking about you know??? And she's been up to (the unit) and she sort of understands the kinds of things I have to deal with when I am here? It's a two way street. And she is a nurse as well, and it's been helpful because of some things she's seen...

In this case, her confidante validated her perception of her husband's condition and of her reactions to the hospital experience.

In addition to validating participants' perceptions of the event, of their experience, and of the patient's progress, close others also facilitated cognitive re-framing. Cheryl described how one of her sisters helped her to re-assess the circumstances of her husband's accident. Her sister re-directed her attention to elements of the event that supported her need to believe that a good outcome was possible and to "focus on the here and now". She recounted:

I have another sister who's a psych nurse and she said, she thinks like me, "Don't go there, don't take stuff there, everybody's different, you can't, you can't think like that you know?"... He has the best care he can get, it's not like he lay on the job site for two hours with nobody there you know?

Participants were not always willing to share trauma-related thoughts with others at this time, especially with children. Cheryl felt the need to be strong for her children and to protect them from her pain and worries. Although she left them out of the cognitive process that she was engaged in, it did not interfere with her ability to work on trauma-related thoughts and emotions.

In some cases however, close others actually interfered with the person's ability to work through trauma-related thoughts. For example, Monique described at great length how she had lived through an abusive relationship with her ex-husband whom she had divorced eighteen years previously. During her son's hospitalization, he took control

of the flow of information, in part because he was knowledgeable about the health care system based on his prior experience as a paramedic. In addition, he took control by monitoring and restricting her access to her son. She said:

He [my ex-husband] wouldn't even let [my son's wife] or myself go and see [my son] after 17 and a half hours on the operating table because he told the head nurse that we were very emotional and we might damage [my son]... He chooses his visitors and he's afraid that [my son] will tell me something, I don't know...

As a result, Monique's interview focused almost exclusively on past relationships with her husband and children, and his controlling and manipulating behaviour. Despite numerous attempts to probe into how she was coming to terms and coping with her son's accident, she seemed unable to focus away from her husband's past and current behaviour. Her lack of access to medical information and to cues from her son by "being there" may have contributed to her inability to reconcile the trauma event with her past experiences and values and beliefs about the world. In addition, she had previous health challenges herself and unresolved past traumas in her life involving her family that may have contributed to her inability to compartmentalize the current experience. Her BSI® as well as both the intrusion and avoidance scores on the IES was above the cutoff for the scales, indicating emotional distress and incomplete cognitive processing.

In some situations, others also interfered with the participant's ability to work through the event by imposing their views about causality. For example, Beverly, whose son was assaulted after drinking with some acquaintances, felt that her family was blaming her for what had happened to her son. She said:

In a way, I feel like they are blaming me for what happened to him, that he'd gone off with these people and that's what happening... Sure it was [my son] who made a bad decision but I feel like they're blaming me so I am blaming myself. It makes me feel like it's my fault but it really is not. That's the way it's been in my life, like I'm the cause. It wouldn't have happened if I had been a better parent.

This interaction with her family forced her to re-assess the event from another perspective, that is, that it was her fault. She began to consider this possibility as

plausible given her own past life experiences and it therefore negatively re-framed her perception of the event.

Another way in which others could facilitate or hinder the participant's cognitive and emotional processes during this phase was how they supported the participant's use of story telling as a strategy to piece together the details of the traumatic event. Most participants expressed a need to speak about the event over and over again and experienced feeling of frustration when others responded beyond listening and validating their perceptions. Cheryl shared:

I'm having a hard time listening to their stories... I'm the one that's in trouble here guys, I don't want to hear about what happened to somebody who had a stroke and was in here for six months and walked out fine, you know, I don't want to go there, right?

In contrast, Cheryl was able to tolerate her son's trauma-related thoughts. She said:

WCB phoned him right away you know, they had counsellors and everything ready for him, and he said he didn't think he needed it. He's been good about talking about it over the last week, talking about the accident, talking about seeing his dad, talking about what he saw, you know, when he walked into that room. I think that's sort of what he needs to do. He understands, that it's something that could happen, it happened, you know. I mean, how often, they spend their whole lives on ladders, I mean, they've all fallen off of them, you know? He was just was unlucky.

When asked if it was difficult for her to listen to her son's stories, she said, "Not at all, in fact I say to [my son] that I want you to learn from your dad. You know, when you, when you crawl up that ladder, put on a harness, you know?" Both mother and son were actively engaged in processing trauma-related thoughts, and discussing thoughts and feelings about the event may have provided an opportunity for them to co-construct an explanation for the event.

However, not all family members were able to tolerate each other's trauma-related thoughts. Nancy shared how her son-in-law, who was a passenger in the car driven by her daughter (the patient), had a need to talk about the accident repeatedly. She described the following feelings:

Like [my son-in-law] needs to talk about the accident... I can't deal with this. Like he says he needs to talk about it, because it makes him feel better, and that's fine. But I don't want to hear about that any more. I know how it happened; I know what a mess she was. I want to quit visualizing that. I want to move on.

The difference between this situation and the previous participant's story above may have been that she and her son-in-law were at different stages in the processing of their trauma-related thoughts and emotions. Driven by a fit between the event and her core belief system that accidents happen for no reason, she wanted to move on to focusing on getting her daughter well again. She did not want to re-engage prior cognitive work. The differences between these situations may also be related to a difference in the closeness of the relationship. However, Nancy did eventually recognize her son in law's need to engage his traumatic experience and negotiated a compromise with him. She explained, "He needs to talk about it, because if it wasn't for him, we wouldn't have [my daughter]... so I can take it in small doses. Like talk about it, but let's not talk about it at suppertime." Although it was difficult for her, she made a conscious effort to support him in this way.

Although a few participants commented on how the nurses had been encouraging by validating their perception of the patient's progress, only one participant specifically mentioned having access to a health care professional if she was upset and needed to talk. In this case it was a social worker. When participants were probed about whether they had experienced this kind of support from nurses, they shared that nurses had not been available to assist them in coping with the experience at that level. Cheryl said:

I realize nursing is a hard, and I think sometimes that they sort of take themselves to other places... They don't want to personalize any of this. And so, maybe it's hard to get to know a family member because then you're personalizing it... That would have been nice [if they had been available to listen to family members] but I have mixed feelings about that and I knew their main concern was [my husband].

Although participants recognized a need to be able to talk to professionals about what they were going through, they also did not want to distract them from focusing on the patient.

Summary: Phase I

This phase was characterized by a pattern of reactions to the traumatic event. Participants experienced a period of initial clarity and action when they learned about the accident followed by a variety of emotions and physical responses, and progressive difficulties in concentrating and thinking clearly. Their notion of time and place became altered and they began to compartmentalize their experience by “focusing on the here and now” in the ICU/neuro ICU. This latter response supported their need to wait and see whether their loved one would live or die. As they waited for the patient to “wake up”, participants engaged in a number of interrelated appraisals aimed at determining the patient’s post-trauma status, evaluating the traumatic event, and the quality and availability of support from others.

Participants’ abilities to gather information about the event and the patient’s post trauma status was facilitated by being physically present at the bedside. Participants looked for cues that the patient knew that they were there and observed for signs of progress in the patient’s condition. Their unique “knowing” of the patient fuelled a belief that the patient could survive his or her injuries. During this phase, information from health care professionals about the event, the patient’s injuries, treatment plans and goals also contributed to their perception of the situation. However, participants did not want information about the patient’s prognosis, especially if this information predicted a grim outcome. At this point, participants actively focused on information that was positively biased which supported their need to believe that the patient could survive his or her injuries. The quality of the pre-trauma relationship was an important factor in facilitating this process. Participants who did not have a close relationship with the patient had difficulty being at the bedside and perceiving subtle patient cues. As a result they relied more heavily on information provided by health care professionals. However, as seen with participants who had a close relationship with the patient, they also had a need to believe that the patient could survive his or her injuries, and were quite distraught as a result of receiving negatively biased information.

As participants gathered information about the event and the patient, they used strategies such as comparing, reflecting, questioning, and story telling to find a fit between their appraisal of the current situation with their past traumatic experiences and

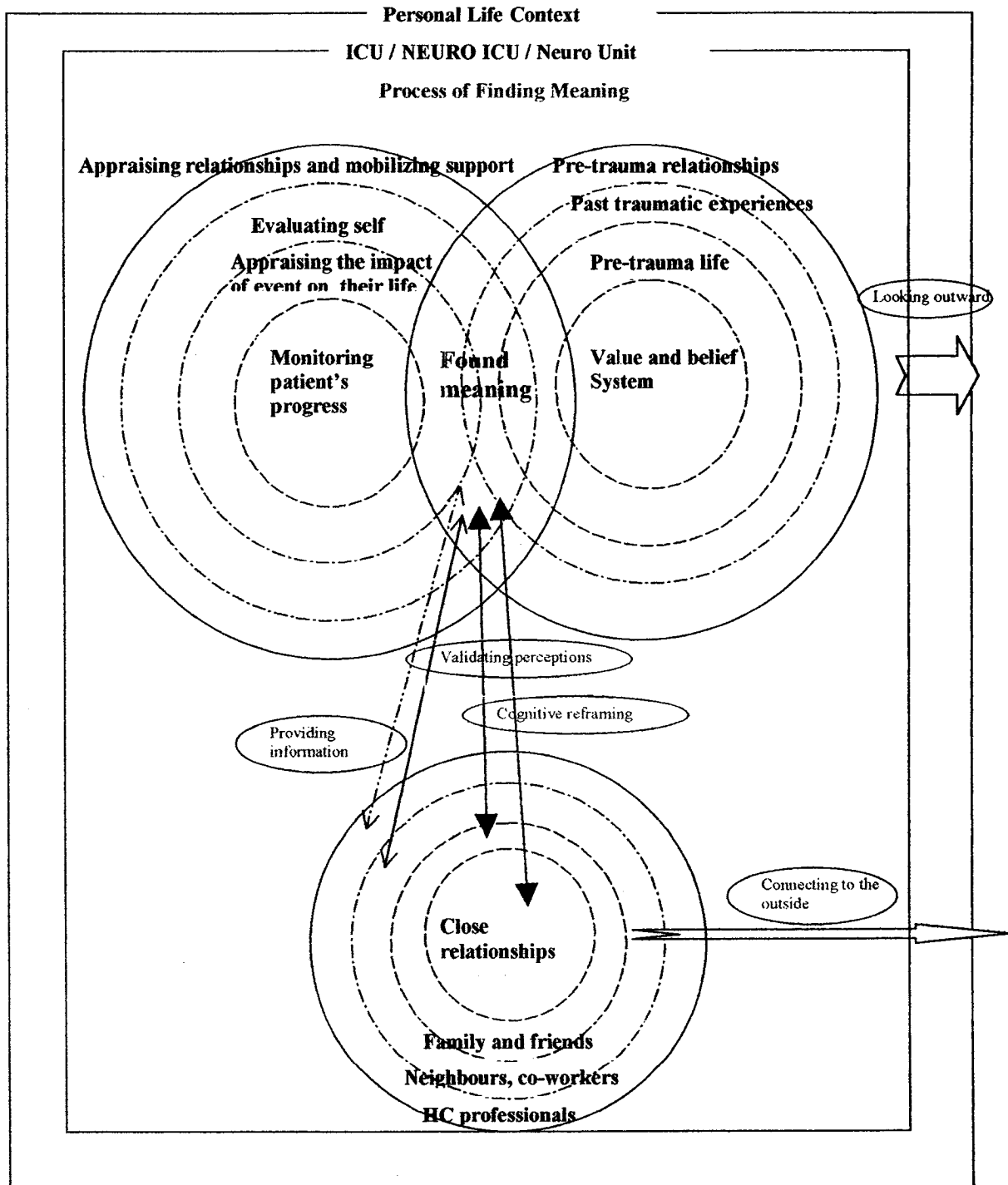
pre-trauma value and belief system. Participants' previous traumatic life experiences appeared to create room for reconciling negative events with their value and belief system. However, when past experiences had not been resolved, and particularly if participants had used avoidance as a coping strategy, they struggled at finding a fit and the effect of negative life events was cumulative. Another factor in the person's ability to work through the traumatic event was how much it undermined the person's values and beliefs. It seemed that the more disrupted the participants' value and belief system was as a result of the accident, the more cognitive efforts were needed to work through trauma-related thoughts and emotions. The process of reconciling their appraisal of the current situation with their past traumatic experiences and pre-trauma value and belief system resulted in an explanation for the event that tended to be positively biased. Furthermore, during this phase, participants tended to keep the level of explanation about the event at the broader level of "life" as opposed to "their life". This was consistent with their need to compartmentalize their experience at this time and to favour uncertainty about the patient's prognosis.

The third level of appraisal made by participants during this phase was an evaluation of the support that they received from family, friends and neighbours, as well as professionals and the health care system. They compared the level of support they received to the quality of their pre-trauma relationships and their expectations for support, which in turn helped them to determine whether they felt comfortable accepting support from others. During this phase, the participants tended to focus on accepting support, rather than mobilizing support, and assistance from others was important because they helped participants to take care of life at home and at work so that they could be with the patient. However, the outpouring of support was sometimes overwhelming for participants and they used strategies to disseminate information and restrict visits from people who were not as closely linked to their family. Participants' willingness to accept support from others was primarily influenced by the closeness of their pre-trauma relationships. Overall, health care professionals were not mentioned as a source of support other than informational support. However, when probed, participants identified ways in which health care professionals had been both supportive and unsupportive, though they tended to focus on staff behaviours and system issues that

interfered with their ability to gather information about the patient and the event and to advocate for their loved one.

One last aspect of appraising support and relationships involved comparing their perception of post-trauma support to their prior conceptualization of the world. As a result of the outpouring of support experienced by participants, most considered the world to be generally benevolent, which in turn contributed to their appraisal of the event. This was also true for those whose values and beliefs about benevolence of the world had been called into question by the assault of their loved one. Although the participants' individual appraisal of support and relationships contributed to this cognitive process, close others also helped by validating and reframing the participant's assessments and experiences. Because others could also potentially interfere with this process if the quality of the relationships had been poor, support was therefore construed as a mediator of the process of finding meaning.

Figure 3 Phase II – “Expanding Perspective”



Phase II – Expanding Perspective

The onset of this phase began when the patient's level of consciousness began to improve and the participant felt that their loved one was going to live. Although patients tended to be transferred out of the ICU at this point, from the perspective of the participants the transition was guided by the patient's increasing level of consciousness as opposed to the change in level of care. While participants continued to focus on the ICU or unit, they began to re-connect with their personal life context and to resume responsibilities at home and at work. They often commented that they needed to "move on".

A number of characteristics differed from the first phase outlined previously. First, there was a decrease in the need to compartmentalize and a broadening of their perspective to consider the "bigger picture" of the patient's post-trauma status. This was accompanied by an ongoing process of finding a fit between the current situation and their prior conceptualization of their world, including what it potentially meant in the context of their pre-trauma life (see Figure 3). Participants also began to evaluate their initial reactions to the event and how they had managed. In fact, all participants tended to be surprised by their ability to deal well with the situation. Participants engaged in comparing their current reactions to their previous coping patterns and to others' coping. During this phase participants continued to assess their support system and began to mobilize support from others more purposefully depending on the quality of their relationships. Each aspect of the model, as illustrated on Figure 3, will be discussed and contrasted with Phase I as appropriate.

Monitoring the Patient's Progress

As illustrated on Figure 3, participants' perceptions of the patient's post-trauma status continued to be central to the post-trauma appraisal process involved in finding meaning. The information obtained from monitoring the patient's condition during this phase assisted mothers and wives in evaluating the significance of the traumatic event in relation to what it might mean to their lives. Participants monitored the patient's post-trauma status and behaviours in comparison to previous life experiences. For example,

Beverly compared her current son's behaviour as he emerged from his coma to her other son's post-coma responses as follows, "This is all happening like with [my oldest son]. It is scaring me. He was being very aggressive when he woke up, swearing? He knows I don't like that kind of swearing." Participants also gauged the patient's status behaviours in comparison to his or her pre-trauma characteristics, including their pre-trauma relationship. Beverly added, "But the next day he was fine! Knowing [my younger son] he's more older, he is older than what [my eldest son] was when he had his injury. So he's more already grown up and responsible you know." The process of comparing the patient's behaviours to her past experiences and the patient's pre-trauma characteristics shaped her perception of how her son was progressing, which in turn influenced her appraisal of the impact of the event.

As seen in Phase I, participants continued to observe the patient intensely for sign of improvement. However, in contrast, participants said they wanted information to would help them understand the "big picture" of the patient's deficits and prognosis. The need to compartmentalize was reduced and their need for information became more future-oriented. This was accompanied by a shift in the level of finding meaning that focused on the implications of the injuries for their lives more specifically. Cheryl illustrated this shift clearly when she made the following request to a nurse working with her husband:

"Now that the shock is over, now that his eyes are open, he's sitting in a chair, can you tell me exactly what his injuries are?" ... I want the big picture, I mean, am I ever going to have him back the way he was? If the answer's no, okay, start telling me that. You know so I can say okay, I need to look at this, or I need to do this... I only need a "might", I don't need "a will be" or anything, "it might", and give me the worse, don't say well things will be perfect, because even I know they won't be.

Although participants were willing to hear the negative at this stage, they continued to focus on the notion of uncertainty about the patient's future recovery in order to leave open the possibility that the patient could recover. Nancy illustrated this when she said: "There is that chance that we won't be one hundred percent. But we're not giving up... And she does awesome in her therapy, like she works hard." Both

Cheryl's and Nancy's comments suggest that sustaining a sense of uncertainty about the patient's prognosis helped them to remain focused on the patient's progress and to maintain their sense of hope.

The irony was that when the patient was in the ICU/neuro ICU, health care professionals were available and willing to give participants the details of the patient's injuries and prognosis. However, once the participants were ready to hear this information, the patient had usually been transferred to the step-down unit or ward where information was not readily available. As a result, participants had to learn how to access the information that they needed, which sometimes created friction with health care professionals. Christine said, "I had to push every time to talk to somebody, they never came to me... And I don't think that it's right." In fact most participants voiced the feeling of frustration searching for medical information, which was intensified by the fragmentation of care. Cheryl said:

The other thing I found is I don't know if he's had the same nurse two days in a row. And so we would go in there and we'd say, "Has he had his CT scan?" And they'd say, "Um, I think. Nope, I know there was an order." Then they said, "I don't think he has one... Let me look, oh no, yeah we cancelled the order." Okay, so a couple days later I was going, "Oh, he had a CT scan? I thought they had cancelled the order?" "Let me look, oh yeah, they did." So that scares you... how he is IS really important to me... Read the chart and know what you are talking about before you talk to me.

In view of the fact that the nurses often did not know the details of the patient's chart and that information about the patient's progress and prognosis was not forthcoming from health care professionals, participants spent a lot of energy navigating the system to get the information that they needed. They said that this had been stressful for them. Participants blamed cutbacks in health care funding, high workloads, poor communication between health care professionals, and fragmentation of care for the lack of access to information. Participants also expressed a need to receive written information in the form of pamphlets, which were not readily available to them. As a result, many searched the Internet for information. Information obtained from health care professionals was important to the participants during this phase because it provided them

with a context for interpreting their own observations of the patient's post-trauma status and behaviours.

As in Phase I, participants continued to observe the patient. They described being intensely watchful for signs of progress in the patient's condition. For example, Nancy described her excitement when she suddenly realized that her daughter could read again. She said:

The other day, when we were down in visual therapy, there's a bed out there and it said, "Return to physiotherapy". And [my daughter] goes: "Replace to physiotherapy?" [The therapist] said, "It says return". She goes: "Oh, return to physiotherapy." Like how could she read that word!

In addition to watching for signs of progress, participants began to gain additional information about the patient's status by "working with" him/her. It was easier for participants to "be with" the patient once he/she had been transferred out of the ICU setting because visiting policies were not as rigidly implemented by staff. However, they often had to negotiate a role for themselves in working with the patient. For example, Cheryl told the story of how she had to convince staff that she could help move her husband up in bed. She added, "So I showed them, and they were fine with that and then they let me." "Being with" and "working with" the patient enabled participants to monitor the patient's progress and also enhanced their ability to re-connect physically, emotionally and cognitively. As they worked with the patient, they began to re-connect through a merging of their respective realities. Nancy described how she joined her daughter in the reality of her confused state. She was able to calm her daughter by connecting cognitively with her in her confused time and space continuum. Nancy continued to journey with her daughter in this way as her level of consciousness improved which also gave her added insight into her daughter's cognitive and emotional status. For example, Nancy described how she needed to guide her daughter step by step through her morning care. As they worked together, Nancy and her daughter shared their feelings with each other. She added, "'Honey isn't this the shits?' I say, 'Twenty-five years ago you learned how to do that, and here we are doing it all over again!'... 'It's terrible!' she says, 'I hate it.'"

As participants worked with their head-injured family member, they also identified ways in which the person that they knew was gradually re-emerging. Cheryl described the following insight, “And the MOUTH! Now I know that it's part of the head injury thing and it will get better. But he's not being totally different than he was before the accident.” The participant’s unique knowledge of the patient’s pre-trauma characteristics shaped their interpretation of the patient’s post-trauma behaviour and hence of his or her condition. Participants monitored the patient’s progress by being watchful for the re-emergence of subtle personality characteristics whereas health care professionals monitored the patient’s progress from the perspective of their experience and knowledge base about the sequelae of head injuries. At times, these differing perspectives created friction between participants and health care professionals, especially when staff did not acknowledge the participant’s knowledge of the patient. After having had a disagreement with staff about her son’s post-trauma behaviour, Cathy described the following insight, “The staff can't see what I see because they didn't know him prior to him going in there. They didn't know what his behaviour was like, and he's pretty close to being normal now... Doesn't listen, quick temper (laugh).” As seen with this example, participants relied heavily on their own interpretation of the patient’s behaviour and progress, rather than the professional’s conclusions.

As illustrated by the above examples, participants worked with their loved one and embarked on a mutual journey through the ups and downs of the patient’s recovery. Some participants described the journey as a “roller-coaster ride” that involved the whole family. As the patient’s level of consciousness and emotions fluctuated, so did the participants’ emotions. Nancy recalls her daughter’s comment at a time when she felt down about her deficits. She said, “The other day she told us, ‘You know I'm one person. I'm going through some stuff.’ And we said: ‘Yes we know you are. And we're going through it with you.’” As they journeyed and worked with the patient, participants reaffirmed their commitment to the patient and became quite protective. In fact, the need to be at the bedside was so compelling that most participants reported feeling guilty when they were not physically with the patient. Beverly described her feelings when a friend convinced her to go out with her for lunch. She said, “I felt so guilty you know? I have to be there with [my son] you know? I feel protective of him right now... It's kind of

weird you know? He's in good hands.” Although she felt that her son would be well cared for in her absence, she felt that she could not leave his bedside. Other participants were not so sure that the patient would be safe in their absence. Cathy illustrated her fears for her son who ignored his swallowing deficit. She said, “I am worried about him! ... He's not supposed to have any fluid, and he's getting up and taking the fluid himself... And he doesn't care! He's thirsty. I worry about that.” Cathy felt protective of her son because she wanted what was best for him and did not want pulmonary complications to get in the way of his recovery. She also worried because the nurses could not watch her son and protect him from his poor judgment when she was not there. This was a common worry for participants once the patient had moved out of the ICU to the ward where the nurse-patient ratio was greater. In addition, because the same nurse was rarely assigned to the patient from day to day, participants were concerned that the staff did not know the details of the patient's condition and they feared for their loved one's safety. The participants' need to protect the patient and to focus on his or her progress was consistent with an increased awareness of the significance of the event in the context of their lives.

Whereas most of the participants journeyed in synchrony with their loved one during this post-trauma phase, as seen in Phase I, participants who had a difficult pre-trauma relationship with the patient continued to have difficulty “being with” and “working with” the patient. They tended to react more negatively to his or her post-trauma behaviours and often sought outside assistance to deal with the patient. For example, Lise described the following encounter with her husband during one of her visits. She said, “At one point he did get violent with me he grabbed me... And once they started giving him something it calmed him down a lot. And they also increased his anti-depressant. And that helped a lot.” She also described returning to work so that she did not have to come to the hospital as often. She said, “There's only so long that you can stare at each other you know? ... I had to go back to work to keep my sanity.” As a result of their poor pre-trauma relationship, Lise had difficulty committing to working with her husband and therefore in monitoring his progress. She relied heavily on the health care professional's observations. For example she said, “He has made a lot of progress this week and once the swelling goes down in his brain, they figure that it's mainly his speech. They don't know how much recovery he'll have with his speech at this

point.” Lise’s inability to attend to subtle cues of her husband’s progress biased her conclusions towards the health care professional’s perspective.

In summary, participants monitored the patient’s progress through reflections about, and comparison of the patient’s post-trauma status and behaviour with past traumatic experiences and the patient’s pre-trauma characteristics. These observations were enhanced by their ability to be at the bedside and to work closely with their head-injured relative. As they reconnected with the patient and journeyed along the fluctuations of his or her recovery, participants began to detect the return of subtle pre-trauma characteristics, which in turn informed their evaluation of the patient’s progress and reaffirmed their commitment to work with the patient. Being able to see improvement in the patient’s condition also fuelled their need for uncertainty and to believe that a good outcome was still possible. Information from health care professionals also contributed to the participant’s perceptions of the patient’s progress. Unfortunately, this information was not readily available and participants had to navigate the system in order to meet this need. However, during this phase, participants wanted to know the details of the patient’s prognosis so that they could determine the impact of the event on their lives and to begin planning. The need for information about the prognosis and a focus on the patient’s progress was in keeping with a shift in focus towards the implications of the event in relation to their lives. As seen in Phase I, the quality of the pre-trauma relationship influenced the participants’ ability to “be with” and “work with” the patient. When the relationship with the patient had been difficult, participants had difficulty picking up subtle changes in the patient’s condition and to make valid conclusions about the impact of the event on their lives.

Appraising the Impact of the Event on Life

During this phase, the participants’ need to speak about the traumatic event had markedly decreased. Furthermore, a number of participants were no longer asking questions that related to why the accident had occurred, why it occurred to their loved one, and who was responsible. Some had settled on one or more explanations for the event that were satisfactory for them whereas others were satisfied with the explanation that there was no answer. What appeared important was the ability to explain the event

within the realm of prior conceptualizations rather than the details of the explanation itself. As a fit was found, the participants' use of questioning and story telling strategies decreased. They described having "moved on". For example, when asked if she asked herself the question "why", Dorothy, whose husband had fallen from a ladder at work, answered the following: "NO, probably 'cause I know accidents happen you know. I don't, have a need to go there, or question, it's not important to me." However, a number of participants continued to evaluate the event in relation to their past experiences and their values and beliefs about benevolence, control, fairness, and justice. For example, Marilyn, whose son had been assaulted, continued to work on issues of justice and responsibility at the time of the second interview. She said, "Those individuals have been raised by a family, those families have been raised by a community, and that community has been accepted by a greater community. So who is responsible? I think we all are. We are all responsible to some degree." A distinct difference with Phase I was that her ideas were more connected and there was a shift in her story to include how her personal life context tied into the explanation. She initially had attributed responsibility for the assault to the perpetrator's community and society in general, and was now considering her own involvement as an integral link in the chain of responsibility for the event. At this point Marilyn was no longer using extensive questioning but rather, validating her own explanation of the event with her value and belief system in the context of her pre-trauma life. In keeping with this shift, Marilyn also expressed a greater concern with issues of selectivity, that is, "why did this accident happen in my life?" At the time of the first interview, Marilyn said, "I haven't asked that question. I don't know why but I haven't. Not once". In contrast, at the time of the second interview, she had asked herself the question and said, "I don't know what the answer is yet. I just know that basically I have been chosen for whatever reason. We'll have to see what the end result is, I don't know." This example illustrates how the search for an explanation continued over time when the event had been difficult to reconcile. However, just like those participants who had found an explanation, Marilyn was able to "move on" to focus on the impact of the event on her life suggesting that finding meaning is more than finding an explanation for the event.

At this time, participants began to notice the world around them. Their world was

no longer confined to the patient in the ICU or neuro ICU. As Cathy illustrated:

I mean when we were first in the hospital, I didn't see anything else but him. I didn't see anybody else's pain or anything. And as things started to change for him and improve for him, I sort of noticed that there were other things going on out there! And they were other people out there in just as much pain as I have, but I didn't see that for the longest time.

Consistent with a shift in focus to understanding the “bigger picture” in the context of their personal life, participants also began to compare the patient’s condition to that of others worse off. Cheryl recalled comparing her husband’s condition to that of a patient with a brain tumour in the same room. She said, “I know [my husband] is sick, I know his head was injured. But I mean, we’re functioning. We’re doing a lot more than a lot of people, especially when I saw the fellow with the brain tumour.” This was a common experience for participants. When asked if they felt that they were better off than other people, all responded affirmatively using a variety of examples that were meaningful to them. Of significance though, Marilyn, whose son had been assaulted, focused on both her son’s luck as well as his misfortune. In comparing her son’s situation to a quadriplegic boy her son’s age on the unit she said: “[my son] is becoming aware of how fortunate he is that his body functions are basically under his control... And yet, at the same time, how unlucky he was, if only the bus had let him off just one minute later you know?” Given that Marilyn continued to be preoccupied by questions about causality at this time, it may be that her vacillations in comparing their situation to both, those better and worse off, indicated continued efforts at making sense of the event.

The overall tendency of participants to compare their situation to others worse off seemed to help them appraise the event in a favorable light. In fact, none of the participants had difficulty identifying one or more reasons why this event had been positive in their lives. For example, all of the participants felt lucky that their loved one was still with them. Gurdeep said: “We are so lucky that my son is still with us”. . Marilyn said that she had felt privileged to “have an opportunity to watch [my son] grow all over again. It’s like watching your kid grow at laser speed... I appreciate every little moment... I feel lucky that I can be here to live these moments with [my son].” Just like Marilyn, many participants viewed the event as an opportunity for a second

chance.

As observed in Phase I, believing the positive and finding positives in the event enabled participants to re-establish or maintain a positive stance about the world and more specifically, in their lives. It also enabled them to focus on the patient's progress and on the more constructive goal of getting the patient well again so that they could resume their lives. It fuelled their energy to continue to work with the patient. It also enabled them to examine their life from a new perspective. Marilyn said, "I think that just being more aware of, and trying to find out where you can continue to make a difference. That's how I will find my resolution about it". As such, her son's injuries caused her to examine her sense of purpose in life. Other participants began to re-assess what was important in their lives. Cheryl reflected on how her priorities had changed and how she felt personally transformed by her experience. Similarly, Cathy said, "And that's totally changed my outlook on a lot of things. Like I'm not going to let the small stuff get in my way anymore because it's not worth it. You know, life is precious and you realize it in here." Participants began to re-examine the beliefs and values that guided their lives and reflected on how the event had changed their perception of the world, of their lives, and of themselves.

In summary, the majority of participants no longer felt a need to speak about their loved one's accident and to use questioning as a strategy to find an explanation for the event. They had been able to find a satisfactory fit between the event and their value and belief system. In contrast, those participants whose way of seeing the world had been more seriously undermined by the event continued to work on finding an explanation that they could be comfortable with. However, their explanations had become more connected and comfortable to them and they spent less time using story telling and questioning strategies. Just like those who no longer had a need to search for an explanation, they were able to "move on" to consider how the traumatic event impacted their values and beliefs about their lives more specifically. As such, their horizon had expanded beyond the hospital. As seen in Phase I, participants' had a tendency to positively bias the information that they focused on. They tended to make comparisons of their situation with respect to others worse off than they were, and to identify numerous reasons why the event had positive outcomes for them and for the patient.

Similarly, participants focused on the patient's progress and maintained a positive stance with regard to the impact of the event on their lives. It helped them to stay hopeful that life would return to some level of normality therefore stabilizing their need for order in their lives. In addition, a number of participants began to reflect on how the event had transformed them personally and changed their outlook on life. As such, it assisted them to re-establish a sense of purpose in their lives.

Evaluating Self

As illustrated on Figure 3, evaluation of the self emerged as a new dimension in the complex appraisal process post-trauma. All participants described their reactions to the traumatic event as well as strategies that they were using to manage at this time. For example, they described a number of emotional reactions such as shock, anger, sorrow, sadness, and guilt. They also described strategies such as talking about the accident, journaling, letting themselves feel, going with the flow, being positive, and using hope, humour, religion, and other strategies. The choice of strategies varied across participants. As they reflected on their reactions and coping strategies, participants embarked on a process of comparing their reactions to how they had coped with past traumatic experiences in their lives. For example, Cathy described how she had lost a brother and her father to cancer within the span of a two-week period. She explored how her reactions differed, but she still saw herself as strong, "It could never be similar. It's totally different. I mean I loved my father and my brother dearly but it's my child. It's still really painful watching him struggle... Physically I'm really feeling it you know? But I'm tough."

In addition to examining their current and past responses, participants compared themselves to other's ability to manage stressful events. Cheryl discussed how she had been able to cope with her husband's accident and how women in general tended to cope better than men. She described a previous car accident where she had been hospitalized for three months. She said, "I look back and I look at how [my husband] was when we had our accident and I was in the hospital. And I don't know if he really functioned... So I think I'm the tougher one and the stronger one." Most participants engaged in a similar process, which led them to the conclusion that they were strong and able to cope with

such a situation better than most people. In fact most surprised themselves with their ability to cope with the accident. In addition to feeling surprised by their strength to make it through this stressful period, some participants reflected on their ability to perform, such as Cheryl who had never driven downtown before but now did so. Even participants who didn't feel they were strong people tended to look at their coping with the current situation in a favourable light. Carol said: "Sometimes I thought I was going to lose it but somehow, you just manage (laugh)... I never thought I was a strong person but I guess I must be". This finding suggests that even if participants did not view their pre-trauma self-esteem as strong, there was still a tendency to re-establish a positive bias to their perception of self.

In addition to comparing their ability to cope with current and past traumatic situations, most participants felt that past situations enabled them to cope better with the current trauma. Nancy shared the following insight, "I've had other things happen in my life, but when I look back, definitely not as traumatic as having a child injured. But I lost a husband when I was very young and it makes stronger people out of you." In contrast, if past experiences and relationships had negatively impacted on how the person viewed herself, the efforts to re-establish core beliefs about the self were more intense. For example, Lise explained how her relationship with her husband had contributed to a negative perception of self and how her husband's most recent accident had caused her to stop and take notice. She said:

People like this [my husband] are manipulative! And I'm starting to realize to what extent this has been affecting me... I think that an accident like this, there is no choice but to step back to a certain point for your own self-protection, for your own sanity... I am starting to realize the extent before, how I waited to have permission to feel whatever I have to be feeling. And I'm starting to realize that I don't have to ask someone permission, to feel how I feel... I think it's made me more aware, I would say more independent, or at least starting to get more independent about letting myself feel what I feel. It's still hard but I am exploring that aspect of it I guess.

Over the course of the interview, Lise spent considerable emotional and cognitive energy working through past relational issues with her husband, and to re-define herself in a way that was a little more positive.

In summary, evaluating the self emerged as a new dimension in the complex appraisal process post-trauma. This finding is consistent with the shift in discovering meaning noted during this phase, that of considering the impact of the event and of the patient's injuries on their own lives. As participants examined their post-trauma reactions and how they had managed during the early post-trauma period, they began to compare their reactions to how they had coped with other stressful events in their lives. They also compared their reactions to those of others. This resulted in an evaluation of self that tended to be positively biased in that they perceived themselves as strong and as coping better than most. Participants who did not think that they had been strong in the past and those who expressed feelings of low pre-trauma self-esteem, also tended to ascribe positive characteristics when thinking about the current traumatic event. In fact, the latter participants engaged in intense cognitive and emotional efforts to re-establish a positive view of self.

Appraising Relationships and Mobilizing Support

During this phase, participants continued to examine their relationships and the support that they received from others (Figure 3). Participants engaged in a process of comparing current to pre-trauma relationships with others, which influenced their willingness to accept support. In contrast to Phase I though, participants began to mobilize support from others. Marilyn described how she had developed delegating skills at work and reflected on how this was more difficult in her personal life:

We all know that basically the most successful people are those who can delegate and get more people involved... But the only thing that I did have to learn was to ask for help. And that didn't come naturally to me. But it came a lot easier because people were very loving.

As a result of the quality of her relationships, Marilyn felt safe in mobilizing help from friends and neighbours during this phase to assist her with everyday chores. Beginning to delegate responsibilities was a common experience across participants at this time. This experience was in contrast with Phase I where they did not know what help to ask for and where family, friends, neighbours and co-workers had to take the initiative to help them take care of life on the outside. The change in how they were now able to both accept

and mobilize support during this post-trauma period is consistent with their readiness to move beyond the hospital and to “expand their perspective” by considering the impact of the event on their lives.

When support from family, friends, and neighbours was available, and participants felt comfortable accepting it, they were better able to focus on the patient because it enabled them to “be with” and “work with” him or her. Although supportive others continued to assist them in taking care of life on the outside, participants began to “move on” and to resume some of their responsibility at home and in the workplace. In fact they stated the need to do so in order to regain a sense of balance in their lives. As Cheryl said: “And that's why I needed to go back to work though, I needed to go back to where there was sanity I needed to go back to do what I'm comfortable doing with people and friends that I have” This finding was consistent across participants.

As observed in Phase I, participants continued to compare the level of support that they received from others to their values and beliefs about benevolence of the world. This helped to reaffirm their beliefs about others in general but also the quality of their own relationships. Participants commented on the value of family and friendship in assisting them through this very difficult time in their lives. Nancy illustrated these insights, “I think that we don't give enough credit to family and friends... Sometimes you know they're there; you know they're in your corner, but you just don't appreciate just how much.” When close others were perceived as supportive, participants were also more likely to accept and ask for help.

Participants also continued to appraise the support they received from health care professionals and the health care system. They assessed the competence of various professionals in relation to the appropriateness and success of the interventions. In contrast with Phase I however, the majority of participants tended to focus on how interventions had not been appropriate. For example, Beverly thought it had been inappropriate for a nurse to suggest her son could go home on a day pass. She described the following reaction, “Doesn't she know what state [my son] is in? ... What if something happens you know like he has a tantrum, I wouldn't know how to handle it you know? ... Well, that's just the nurse. She didn't know what's happening with him you know?” Beverly felt protective of the patient, but she was also worried that she couldn't

handle the situation. This example illustrates how the participants called into question the appropriateness of interventions and the staff members' competence. Participants also worried that the patient's best interests were not always central to the decisions that professionals made about interventions. Christine described the following experience:

The feeding tube came out one night and the next morning, they tried to put it back and they couldn't. So the doctor said, "Well, maybe we'll start feeding him". So they did with baby food and thickened water and stuff like that... Well after a few days of baby food, he was hungry you know? ... So we did another test and it was all mashed food after that and I had to ask for that? And then, I had to ask for more solid food again. Otherwise he would still be on baby food.

As illustrated by this example, participants did not perceive that interventions were based on a plan of care that was patient-centered and as a result, they felt the need to take on the role of advocating on behalf of the patient.

Participants continued to describe how hearing mixed information from professionals about the patient's status and treatment plans frustrated them. This led them to question the validity of the professional's assessments. For example, Christine recounted:

Like he used to say, "I cannot sleep here, I'm so tired" and then I would ask the nurse and she would say "He had a really good night of sleep". But you know, it doesn't mean that because he was in his bed he was really sleeping, so they wouldn't know.

Many participants reported having conflicting perceptions of the patient's status from health care professionals, and most of the conflicts arose because the participants had concerns that the patient had been moved prematurely from the ICU. For example, Cheryl said, "The first few days were sort of hard because he wasn't really ready [to be in the step down unit], You know, he was very confused still and he would sort of slip down into his bed. They [the nurses] would sit down with their back to him and I just sort of worried about that all the time." Cheryl's perception of her husband's condition left her worried and fearful for his safety. Many participants also reported feeling ignored by health care professionals, particularly if the relationship had been strained. Christine described how health care professionals, and more specifically the physician,

had been avoiding her in part because she had resisted medical pressure to discontinue her husband's life support while in the ICU. She told a story about how she made the physician face her again. She recounted:

Two weeks and a half ago, I was determined to talk to him, I haven't seen him for two weeks... I was standing there and he was writing a report and I wasn't going to disturb him but I was going to wait as long as it took until he turned around and saw me you know? ... So he saw me, and he came towards me in the usual way, shaking his head and he said, "I'm really happy to be able to admit that I was wrong". And that was good of him. So that made it all OK then, I'll never forget that.

Christine also felt frustrated that nurses were protecting the physician by limiting her access to him. She said, "The nurse had said that I wouldn't be able to talk to him. So I thought I don't care, I'm waiting." This example attests to the importance of an open and collaborative relationship between the family and professionals in shaping a supportive environment for families.

Although participants tended to make comments about how health care professionals had not been supportive and did not always have the patient's best interest at heart, most attributed the difficulties to aspects of the health care system rather than intrinsic to the professional. They spoke about the fragmentation of care, which interfered with the continuity of the patient's care and the flow of information. They were mostly concerned with nursing staffing patterns and workloads. As Christine described: "We had the same nurse two days or three days if we were lucky." As a result participants worried that because the nurses did not know the details of the patient's history and chart the patient would not receive appropriate care. They were often re-directed from professional to professional and felt that nobody had a complete picture of who was responsible for the patient and what was happening with his or her care. Participants also spent inordinate efforts in "figuring out" workload patterns. As Dorothy described, "They were in the four bed ward and this nurse was in there, so I just assumed she had four beds, but she didn't ... I didn't even know who his nurse was!!... I guess when they take breaks then there's one looking after everybody." These examples illustrate how system structures made it difficult for participants to access the information

that they needed about the patient's progress and treatment plans. They needed these data to gauge the patient's progress and to appraise the event in the context of their lives.

Participants were further frustrated by the staff's inability to cope with heavy workloads and by the lack of availability and access to services. For example, Christine described how staff had confronted her because her husband had been restless following his transfer to the nursing unit. She said:

His nurse was like beside herself, she couldn't keep an eye on him every second of the time. And then the social worker was after me like "somebody will have to be with him 24 hours a day. We cannot do this!" And I got really upset because it was like too much at me in one shot! Like both of them within ½ an hour like they came to me when I got there on Tuesday morning you know? And so I burst into tears, I didn't know what to do like you know? Fortunately the head nurse that day was wonderful as she had him as a patient for a few days before herself and so she talked to me and that's when I burst in tears, and I said 'I cannot do more than what I do at the moment' like you know, 'I'm just exhausted' and his mom had left and she would be back in a few days, and I was on my own, the kids were into school you know? So anyway, so to the social worker I said 'Don't you have any sitters you know in this hospital?' I knew that because of my experience with my mother. And she said 'Oh yeah, we have a few but you know, the funds are cut and stuff' and I said 'Shouldn't be my fault, you know?' And I'm thinking, 'Well, he doesn't get it, somebody else will get it!' I mean, the funds are there for that right? So... the head nurse, she ordered one and he had like a sitter for 24 hours a day for the next week.

Participants did not think the decisions were driven by the patient's and the family's needs but rather, by the needs of the system. Although, as seen above, many individual nurses did make a difference to the quality of their experience, participants felt that they did not get appropriate action until they had an emotional breakdown. In fact, they tended to be consumed by the lack of support from health care professionals and system structures that interfered with their need to access information and to feel that the patient's best interest were driving treatment decisions.

In addition to appraising their relationship with others, including health care professionals, participants also began to appraise their family relationships. They engaged in a process of comparing the quality of their pre-trauma relationships back and forth with their current relationships. Gurdeep illustrated this back and forth process through the following example:

We're very close to our family... I have nephew here, his family. You know, his wife and him are always there when we need them. They are the ones who took us to the emergency that night. And my daughter came from England. She's a doctor... She's helping in any way she can... When he was small, she was like a second mother to him...

Gurdeep also commented that her son's accident had made them closer as a family. This experience was common across participants who had described their pre-trauma relationships as close.

In contrast, accepting and mobilizing support from family continued to be perceived as risky by those participants who did not feel that their relationships with others had been close pre-trauma. For example, Beverly had described her relationship with her family, and with her sister in particular, as controlling. They were also blaming her for her son's accident. She said, "Yeah they're here but to what extent they will be willing to help, by doing things and going there... I know that I can ask for help but I don't want to." The pattern of pre-trauma relationships continued for this family and as a result, Beverly felt that she was on her own in coping with the current situation.

As the patient's level of consciousness began to improve and participants began to perceive a re-emergence of the patient's pre-trauma characteristics, they also began to appraise their relationship with the patient. Nancy reminisced about the closeness of her pre-trauma relationship with her daughter. She said, "I mean as child, she would not leave my side. She would be in tears. And so there has always been a very, very strong bond. Always." Nancy felt that the closeness of their relationship enabled her to be supportive of her daughter and hoped that they could both draw strength from it. All of the participants who had perceived their pre-trauma relationships as close commented on how the event had made them stronger and closer to the patient. This enabled them to "be with" and "work with" the patient, as well as to re-connect with the patient and to

begin to re-establish a relationship as a family. Nancy added: "I would say it's almost like re-bonding with her again. And then also this time now, you're bonding with [my son-in-law] too?" As participants worked at re-connecting with the patient they began to realize how the relationship had been altered, at least momentarily, by the trauma in their lives. Beverly observed, "It's like when he was just little?" However, she did not feel upset by this change in their relationship. She added, "I think it's like giving you another chance, do something right? I don't know, giving more love or giving more care?" As seen in Phase I, when the quality of the pre-trauma relationship had not been close, participants continued to have difficulty "being with" and "working with" the patient. This in turn limited opportunities to re-connect and to re-establish relationships with the patient and the family.

In summary, participants appraised the support that they received from others, including health care professionals, and their relationships with family, friends and the patient. In contrast with Phase I where participants evaluated support with the goal of determining whether or not they could accept the support of others, during this post-trauma phase, they also began to mobilize support. However, as seen during Phase I, the quality of the pre-trauma relationship with others was key to their willingness to mobilize support from others. The assistance of others was important at this time because it helped them to resume some life responsibilities while continuing to "be with" and "work with" their head-injured family member. It also helped them to restore beliefs about the benevolence of the world and more particularly the value of family and friendship. These changes were in keeping with the shift noted during this phase where participants began to consider their lives beyond the hospital unit. At this time, participants also attempted to mobilize support from health care professionals. However, most participants reported feeling frustrated by a lack of accessibility to information, conflicting perception of the patient's progress, and a lack of consideration for their unique perspective of "knowing" the patient. Furthermore, participants felt that health care decisions were made from a system-focused perspective rather than being driven by the patient's and the family's needs. Finally, participants appraised their relationship with their close others and the patient by comparing the quality of their pre and post trauma relationships. As they engaged in this process, they began to reconnect with the patient and with close others in

their lives. As seen in Phase I however, the quality of the pre-trauma relationship was a key determinant to their ability to do this. If they had difficulty “being with” and “working with” him or her, this limited their opportunity to re-connect.

The role of support in the process of finding meaning. As observed during Phase I, participants not only continued to reconcile their appraisal of the support and relationships with pre-trauma relationships and values and beliefs about benevolence of the world, but support continued to play a mediating role in the participant’s search for meaning (Figure 3). The input from others helped them to validate, and at times re-frame their thinking about the emerging re-conceptualization of their world and more specifically of their lives. In contrast with Phase I however, participants were able to identify more precisely how others assisted them in making sense of their trauma-related thoughts and emotions. Participants spoke about having someone with whom they could share fears and hopes. For example, Cathy described how a close friend helped her to understand her younger son’s reactions to his brother’s injuries. She said:

Sometimes you have blinders on and you only see what you see... And she sees things that are going on in my life differently than I see them... Just sitting down and talking to her, and realizing where my other son is coming from.

As seen in Phase I however, participants who had difficult pre-trauma relationships with others continued to feel alone and to see risks in confiding in others. However, they began to seek alternative confidants that would validate their experience and help them re-frame their thinking. Lise, who was not close to her own family or her husband’s family described the following interaction with a distant friend whom she felt comfortable and safe confiding. Her friend who had had a difficult married life herself gave her permission to be angry, and Lise noted, “Relatives tend to have certain expectations whereas friends, they can be more objective you know?” Lise also shared her feelings with the grief counsellor in her home community and added that participating in the research project had been helpful sorting out her reactions and thinking about this situation in her life. Another participant who did not trust her family enough to share her emotions and feelings with them used bibliotherapy to understand and validate her experience. Beverly said, “Books are helpful for explaining things to me, I want to ensure that I’m feeling what I’m reading, not what someone else is reading to me or

telling me?” As seen by the above examples, in the absence of close others to confide in, participants sought and found other means of validating and re-framing their perceptions of the patient and of their experience with the traumatic event.

A number of participants gave examples as to how health care professionals validated their perception of the patient’s progress, although, as described earlier, many questioned the accuracy of the professionals’ assessments. However, none of the participants commented on how nurses and physicians assisted them in validating and re-framing their own experience of the traumatic event. In fact, when asked, participants felt that health care professionals, except for the psychologist or social worker when available, did not have the time to pay attention to the family in this way. Beverly said, “I know here, they’re too busy, too many patients you know, too much for them to do... They do what they have to do to the patient; they don’t have that time for you.” While family members said that they would have appreciated input from health care professionals, many participants were concerned that it might have distracted staff from focusing on the head-injured patient. In response to whether she would have found it helpful to have had the support of professionals in dealing with her thoughts and emotions about the accident, Cheryl responded, “ Yes, but I have mixed feelings about that. I knew their main concern had to be (my husband)?” Although most participants said that they would have welcome assistance from health care professionals, none described this as an expectation. Moreover, none of the participants described having experienced family-centered care during the patient’s hospitalization. Rather, as previously described, family members more readily spoke to how health care professionals and the health care system interfered with their need to shift their perspective and understand the “big picture” of what this all meant in the context of their lives.

Summary: Phase II

This phase was characterized by a need to “expand their perspective” based on an appraisal that the patient would survive his or her injuries. Participants described a greater need to obtain information about the patient’s prognosis so that they could place the event and the patient’s deficit in the context of what it was going to mean in the

context of their lives. Participants monitored the patient's progress through reflections about, and comparison of, the patient's post-trauma status and behaviour with past traumatic experiences and the patient's pre-trauma characteristics. These observations were enhanced by their ability to be at the bedside and to work closely with their head-injured relative. As they reconnected physically, emotionally and cognitively with the patient, participants began to detect the return of subtle pre-trauma characteristics, which in turn informed their evaluation of the patient's progress and reaffirmed their commitment to work with the patient. Being able to see improvement in the patient's condition also fuelled their need for uncertainty and the belief that a good outcome was still possible. They also assumed the role of advocate and protector to ensure that the patient's progress continued to move forward. As seen in Phase I however, the quality of the pre-trauma relationship influenced the participants' ability to "be with" and "work with" the patient. When the relationship with the patient had been difficult, participants had difficulty picking up subtle changes in the patient's condition and making valid conclusions about the impact of the event on their lives. Information from health care professionals about the details of the patient's condition and prognosis also contributed to the participants' perceptions of the patient's progress and of the impact of the event on their lives. Unfortunately, this information was not readily available and participants had to navigate the system in order to meet this need.

During this phase, the majority of participants no longer felt a need to speak repeatedly about their loved one's accident and to use questioning as a strategy to find an explanation for the event. They had been able to find a satisfactory fit between the event and their value and belief system. In contrast, those participants whose way of seeing the world had been more seriously undermined by the event continued to work on finding an explanation with which they could be comfortable. However, their explanations had become more connected and comfortable to them and they spent less time using story telling and questioning strategies. Just like those who no longer had a need to search for an explanation, they were able to "expand their perspective" to consider how the traumatic event impacted their values and beliefs about their lives. As seen in Phase I, participants had a tendency to interpret the information positively. They tended to make comparisons of their situation with respect to others worse off than they were, and to

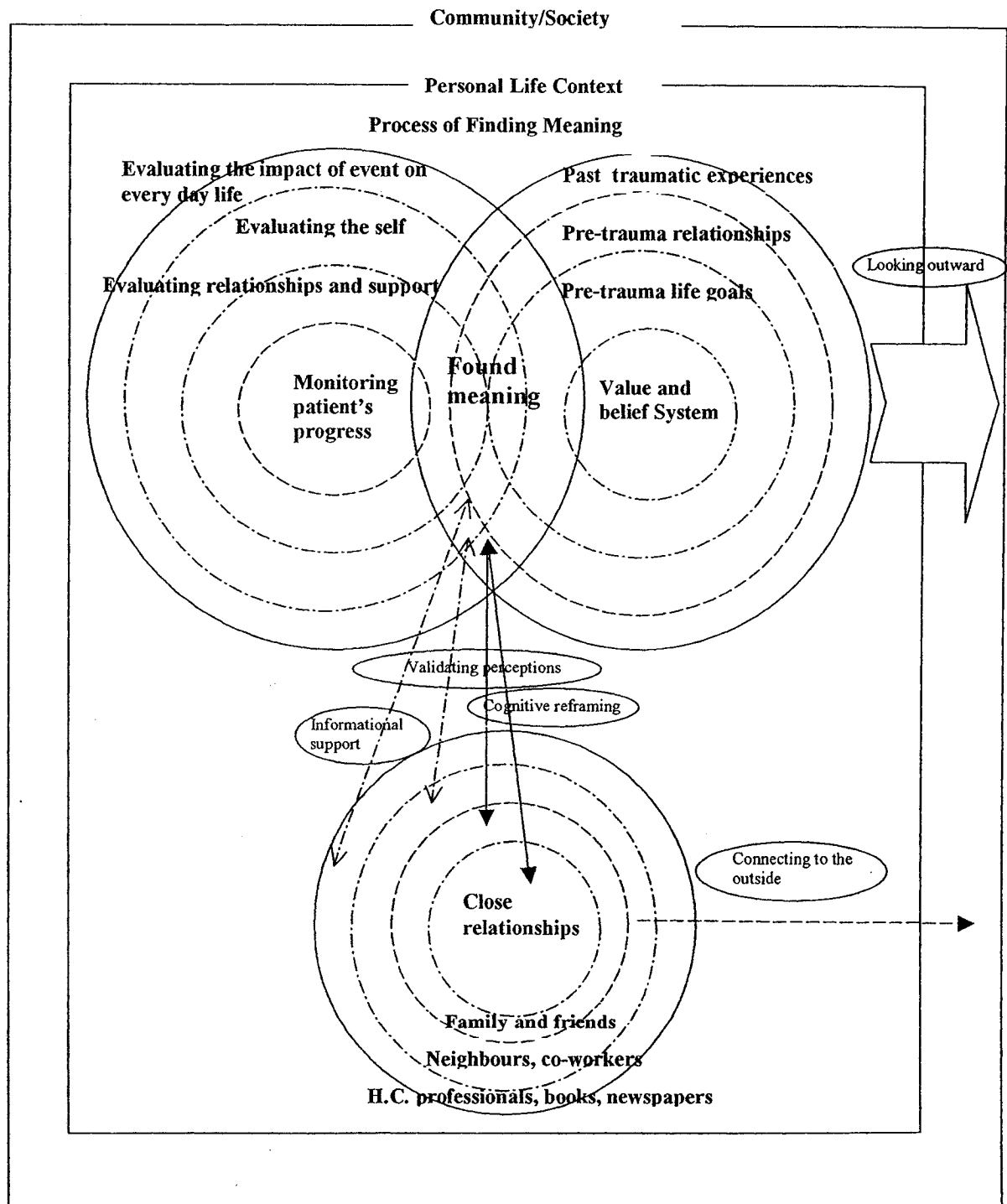
identify numerous reasons why the event had positive outcomes for them and for the patient. Similarly, participants focused on the patient's progress and maintained a positive stance with regard to the impact of the event on their lives. It helped them to stay hopeful that life would return to some level of normality. In addition, a number of participants began to reflect on how the event had transformed them personally and changed their outlook on life. As such, it assisted them to re-establish a sense of purpose in their lives.

At this time, participants also began to examine their post-trauma reactions and how they had managed during the early post-trauma period. They began to compare their reactions and how they had coped with other stressful events in their lives. They also compared their reactions to those of others. This resulted in an evaluation of self that tended to be positively biased in that they perceived themselves as strong and as coping better than most. Participants who did not think that they had been strong in the past and those who expressed feelings of low pre-trauma self-esteem, also tended to ascribe positive characteristics to how they had coped with the current traumatic event. In fact, the latter participants engaged in intense cognitive and emotional efforts to re-establish a positive view of self.

Finally, supportive others continued to be important in enabling participants to "be with" and "work with" the patient and to help them in taking care of life outside of the hospital although during this post-trauma period, they began resume life responsibilities. In contrast with Phase I where participants assessed whether or not they could accept the support of others, during this post-trauma phase, they also began to mobilize support. However, as seen during Phase I, the quality of the pre-trauma relationship with others was key to their willingness to mobilize support from others. The support from others also helped them to restore beliefs about the benevolence of the world and more particularly the value of family and friendship. At this time, participants also attempted to mobilize support from health care professionals. However, most participants reported feeling frustrated by a lack of accessibility to information, conflicting perception of the patient's progress, and a lack of consideration for their knowledge of the patient. Furthermore, participants felt that health care decisions were made from a system-focused perspective rather than being driven by the patient's and the family's needs.

During this period, participants also appraised their relationship with their close others and the patient by comparing the quality of their pre and post-trauma relationships. As they engaged in this process, they began to reconnect with the patient and with close others in their lives. As seen in Phase I however, the quality to the pre-trauma relationship was a key determinant to their ability to do this. Furthermore, support continued to play a role as a mediator in the process of coming to terms with the situation in the context of their prior conceptualization of the world and of their lives. In contrast though, participants were better able to articulate how others helped them make sense of trauma-related perceptions and thoughts through validation and re-framing. Even those who reported difficult relationships with others in their lives found creative ways of obtaining validation and re-framing support.

Figure 4 Phase III – “Resuming Life”



Phase III – Resuming Life

This phase began once the patient was first re-introduced to the home environment either by being discharged home or by going home on pass from the hospital or rehabilitation centre. During this phase, participants focused on what it was going to be like to have the patient home again, and how their lives needed to be altered and adjusted as a result of his or her deficits. As a result, the main focus of the complex post-trauma appraisal process was the patient's progress, and their relationship and social context. As a result, these were illustrated as central on Figure 4. Although evaluation of self and of the event continued to be part of the process, they were less prominent. As participants worked through these concerns, their search for meaning in the context of their lives continued. The process of finding meaning in Phase III will be discussed and contrasted with Phase I and II as appropriate.

Monitoring the Patient's Progress

Participants expressed a need for information from health care professionals about what to expect when they returned home. However, most of the participants received very little information at the time of discharge about what to expect and how to work with the patient. Lise said, "When it was time for [my husband] to come home from the hospital, they sort of said, "OK, time to go home, here is your prescription".... What happens to us now? ... I just didn't know what to expect at all." This experience was not uncommon among participants and most were frustrated by the lack of access and planned follow-up after discharge. Moreover, most had lost contact with the health care system after the patient's discharge because they were placed on a waiting list for rehabilitation services. They felt abandoned by the system and worried that having to wait would negatively impact on the patient's progress.

As seen in Phase I and II, and in keeping with the lack of information from health care professionals, participants continued to rely heavily on their own observations of the patient in order to determine the extent of his or her deficits. In fact, they began to feel more accurate in their observation of the patient's progress, particularly once the patient returned to the home environment. Christine told a story about how she came to realize

that her husband's cognitive function was better than she had observed in the hospital. She said:

He used to order some books for work at the mall at the bookstore and about two weeks ago, he went to the mall and asked if some of the books had come in...

Our older son said the guy went along with it and checked and so there was nothing in. So I said OK, it could have happened. So this weekend, we go back to the store and the lady is holding a book in the air with his name on it (giggle)! He knew!!! So I feel really really good.

This example highlights how Christine was better able to gauge the extent of her husband's deficits in the context of their everyday life. Moreover, the example also demonstrates how participants felt comforted and encouraged when they could re-connect with the patient as the person they once knew in the context of re-emerging past life patterns.

At the same time, there was an increased awareness of how the patient's deficits impacted their everyday life. During Phases I and II, participants focused almost exclusively on the positive aspect of the patient's progress. However, during this phase, they began to take notice of how the patient's deficits impacted negatively on everyday activities. Cheryl described the following insight, "He used to be really good at the remote on the TV? And we got a satellite dish just prior to the accident and so it's now hooked up. So he's really confused. He just can't handle that at all." As seen in this example, participants continued to compare the patient's post-trauma behaviours to pre-trauma characteristics, but this time the context of everyday life gave her more insight on the nature and extent of his limitations. During this phase, participants also continued to gain important information by "working with" the patient. For example, Cheryl described how she helped her husband explore and re-frame his experience of working with the speech therapist, and how she gained important information about his insight, his current abilities, and his potential to improve. She recalled the following conversation with her husband:

He said " You know, there were lots of things I didn't know today, she had me read stories today and then explain to her what I thought the stories meant" and he said "I had a hard time with that, a really hard time with that". I said "Look [my

husband], we'll have to work with you on that. If we don't test you or keep trying, we won't know that". And he says, "Oh, Ok" he said "But I never was very good at doing that (laugh) you know, at school?" I'd say "Yeah, I know. But we have to be able to read and understand", "Oh, Ok". If he didn't have her there, he would not confront this deficit. And that's where she's making him go, which is good. And he needs to do that.

This exchange was also an opportunity for Cheryl to make explicit her expectations that they need to work together at getting him better. This family was one of the lucky few to have been able to access rehabilitation services in a timely manner, in part because it had been funded through the Worker's Compensation Board. As a result, they were able to work with the patient in a meaningful manner and to validate perceptions with the health care professionals involved in the care.

As the patient was re-introduced to daily life and participants came to a fuller realization of how the patient's deficits would impact daily life, they became vigilant and protective of the patient. Beverly recounted her worries at leaving her son at home to go to work. She said, "The only thing is I have to know where he is, what his plans are, how's he's going to get there, if he has to be picked up, or things like that." All participants worried about leaving the patient alone, especially if they felt that the patient's judgement was impaired. They also felt protective about re-introducing the patient into the public arena. Cheryl described her concerns about going out to dinner with her husband. She said, "If we go into any kind of a restaurant that's large or open... It causes him some anxiety. So he's better at home and he's better one on one... We are very selective as to where we go." She also realized that her husband's behaviour was inappropriate in a social context and she wanted to protect him from the reaction of others and conserve her own energy. As seen in these examples, observing the patient's reactions within their social context provided participants with further information about the patient's status and his or her readiness to resume everyday life. As a result, they re-adjusted everyday life and re-integrated the patient into life in a careful and measured manner. For example, Cheryl explained how they had adjusted her husband's role in the family business. She said:

I talked to him and said that once he got better, we didn't want him climbing ladders and working the tools. He could get the jobs [i.e. contracts] once he felt comfortable in doing that, hem but his role as far as the business was, was what was going to change. He didn't answer us right away, and probably I think the next day he came back to me and said "Yeah, I'm fine with that, if that's what [our son] and you want to do, I'm OK."

Although participants continued to believe in the patient's potential to recover, they also began to readjust their own expectations of the patient based on their appraisal of the patient's ability to resume daily activities. They also began to realize the full scope of the patient's deficits and recognized that their expectations of the patient's recovery had been overly optimistic. Cathy said, "But it is not what I expected. I think I had some really unrealistic expectations. I expected him to be 100%." By recognizing the need to be more realistic, participants readjusted their expectations of the patient and of their lives.

In summary, although participants felt unprepared to work purposefully with the patient upon discharge from the hospital and felt abandoned by the health care system, they soon began to take charge of resuming life as best they could. Once they could observe the patient in the context of every day life, they began to evaluate the full extent of his deficits and recovery more accurately. Participants could identify the re-emergence of the patient's life patterns more easily, which was a source of comfort and hope. At the same time, they could pick up subtle deficits that impacted their ability to resume every day life. As a result, they worried about the patient's safety to be alone and they felt protective of the patient in public. Most participants limited the patient's exposure to social situations. In addition, they also began to re-adjust their life routines. Although they did not give up hope for significant improvement, participants began to realize the need to be more realistic about their expectations for full recovery. They therefore began to re-adjust their expectations of the patient and to consider that their life goals might also have to change.

Evaluating Relationships and Support

Participants engaged in a process of comparing and evaluating past and current relationships. They readily identified how those close to them continued to provide instrumental support that helped them keep the home and work context functioning. More specifically, others provided respite and assisted participants in keeping an eye on the patient while they were at work. Cheryl said, "I have enough neighbours, we're in a cul-de-sac and we've all been together for seven years... So he's not totally alone and they'll call me if there is anything. Everybody is keeping their eyes and ears open." Aside from this kind of assistance, generally speaking, levels of support returned to pre-trauma levels as participants resumed most of their life responsibilities. Even though participants appeared to limit their social network because of the patient's deficits and behaviour, they did not feel lonely. On the contrary, limiting social contacts at this point helped to relieve some of their stress as they worked at their own pace to re-integrate the patient and themselves into their lives and social context. As seen in Phase II, participants who had people in their lives who were very close to them pre- and post-trauma described those bonds as stronger and as helpful in assisting them to adjust to the changes in the patient and in their lives. Many participants said that they did not want to take advantage of others so they were careful in determining how much they accepted and mobilized assistance. Those who had difficult pre-trauma relationships continued to avoid accepting and mobilizing assistance.

Participants also assessed the level of support from health care professionals and were frustrated by a lack of access to services. Most of the patients were sent home and placed on waiting lists for either inpatient or outpatient rehabilitation services. This was a source of frustration for participants, as they did not feel prepared to care for the patient and did not have a clear idea of what services the patient needed and when these would be available. The lack of access and follow-up placed participants and their head-injured relative in a "hold" situation. Carol illustrated the frustration felt by many of the participants. She said:

I have no clue! When is he supposed to be ready to go out [of the house]? I don't know! There's no follow-up booked, there's nobody that contact people... I talked to the social worker the last week that he was in the hospital, [the rehabilitation

centre] was aware of him but that there wasn't any room... I have heard nothing over the last two weeks since we left the hospital. I know that there's been cutbacks but there is no excuse for this. I'm not sure who to call or what to do...

If we knew, we could may be make more concrete plans!"

As a result of the wait for rehabilitation services, they were unable to plan for a return to a more normal life. As well, Carol was not receiving validation from professionals about her son's condition and she was unsure about his deficits. She said, "I have no idea about the state of his health right now". In addition, Carol did not have much support from others in her life, including her husband with whom she had a detached relationship. The lack of professional support therefore isolated her further and added considerable burden for her. Only two of the patient received rehabilitation services in a timely manner after discharge from hospital.

As participants began to resume daily life, they began to reflect on how their relationship with the patient had changed. Both mothers and wives expressed their concerns about the changes in the relationship albeit from a different context. Cheryl shared the following insight about her marital relationship, "Well, I don't feel that I have that comfort from him, the support from him, strength that I would need if something was to happen? ... I feel like I now have four children, not three?" Similarly, Carol shared how her relationship with her son had regressed. She said, "Just before this happened I was just getting to the point where he was going to be finally responsible for himself and I can start doing things again... now I feel like I'm back to when he was younger again." Both examples illustrate a more dependent relationship between the participant and the patient, which resulted in a feeling of loss. In the latter case, the pre-trauma relationship had been somewhat difficult. When this had been the case, participants were less tolerant of their loved one's post-trauma behaviours and how it was impacting their everyday life. For example Lise, who had experienced a strained marital relationship with her head-injured husband, said, "I just find him acting more dependent ... Claustrophobic you know? ... He had his job and I had mine and there's a certain amount of space I guess, and all of a sudden, he doesn't have anything to occupy himself with." The couple had difficulties communicating and being with each other prior to the accident and his more dependent post-trauma state increased tension in the couple. She added:

He's been worrying about "Am I gonna leave or not" ... He'll say something to put himself down, about how stupid he is, you know? ... At the beginning he said a lot of things like that and, I probably haven't been as honest as I could have been.

Difficulties in the relationship prior to the accident made it more difficult for Lise and her husband to re-adjust their relationship and to resume their life together. She also found it more difficult to be supportive of her husband and the marital difficulties became more pronounced when they returned home. In contrast, when the pre-trauma relationship had been strong, there was a commitment to work with the patient and to connect by readjusting their relationship. For example, in contrast with the above participant, Cheryl was able to reassure her husband about her commitment to him. She said:

He said to me "Is there a big difference in me?" and I said "No, not a big difference. You are the same old [husband] you always were." "I was worried, I thought you might leave me" he said. I said "Why would I do that? When you opened your eyes, I decided to keep you!" (laugh). And I said "You've improved every day since." "Oh, OK" he said.

Similarly, mothers who had a good pre-trauma relationship with their child were also able to reassure their child. Nancy described how her head-injured daughter felt bad because her accident had interrupted their holidays. Nancy responded to her by saying, "Honey you had an accident, and that's all it was... And we're here for you." Parents who had a good pre-trauma relationship were also able to adjust their lives by welcoming their child back into their lives and working with him or her. Gurdeep described, "We have a bathroom on the ground floor, and he has a bed in the family room... He can shower himself, and we help him. I put oil on his body to help him relax, and my husband he helps him with the shower." As seen in this example, mothers adjusted their lives to resume their former role as parents, at least temporarily. Again, this was easier if the pre-trauma relationship had been close.

Participants also described how family roles and relationships needed to change as a result of the patient's post-trauma status. Cheryl described how her son took over the family business earlier than expected and she expressed her willingness to help. In contrast, changes in the family's relationships were not easy if there had been difficulties

with the pre-trauma relationships. Cathy described her feelings as her ex-husband returned to provide support to their son. She said, “So, like his father has come in like the knight in shining armor after not having been in his life for seven years, not helping supporting him or whatever, and all of a sudden it's like he's taken over.” Cathy proceeded to describe how her husband’s return had disturbed family dynamics and how her younger son felt uncared for and ignored by his father who focused on his head-injured brother. She worried that her youngest son began to verbalize resentment towards his head-injured brother as a result of her husband’s attention. The family’s structure and dynamics had been altered and this caused them all distress.

In summary, participants continued to compare and evaluate pre and post-trauma relationships and support. Although all participants had resumed their roles and responsibilities in their lives at this point, the assistance they received from others continued to be important in helping to keep the home and work place functioning, and to keep the patient safe. As seen in Phases I and II, their ability to accept and mobilize support was dependent on the quality of their pre-trauma relationships with others. Although there was a tendency during this phase for participants to limit their social network to conserve energy and protect the patient from the reaction of outsiders, they did not feel isolated. On the contrary, it enabled them to re-introduce the patient to everyday life in a measured and controlled manner. Participants also appraised the support available from health care professionals. Unfortunately, all but two participants were awaiting rehabilitation services and had been disconnected from the system while they waited. This caused them worry and frustration in addition to placing their lives on hold and therefore making it difficult for them to resume a more normal life pattern.

In addition to appraising social supports, participants began to examine the relationship with the patient and how it had changed as a result of the traumatic event. Both mothers and wives expressed concerns with these changes. However, if the pre-trauma relationship had been close, they were better able to work with the changes in the patient and to commit to him or her. Relationships that had been strong prior to the accident were perceived as stronger after the accident whereas poor relationships tended to become further stressed by the changes in the patient. Changes in the participants’

relationship with the patient also impacted the whole family and roles and relationships needed to be re-negotiated, at least temporarily.

The role of support in the process of finding meaning. As observed during Phase I and II, support continued to play a mediating role in the participant's search for meaning (Figure 4). Participants continued to seek validation from close others about how the patient was doing in the context of every day life. Health care professionals, when accessible, were particularly helpful in helping them to re-frame their expectations of the patient's progress. Cheryl gave the following example:

Everybody kept saying to me, "It's too early", and I'd say "I don't know if it's early, I've never done this before". The WCB rehab. said, "It can take two years before he's plateaus!" So she said, "Just go slow" you know? So I said to myself, "OK, stop setting such high expectations for yourself and just relax. Let him look after himself too, he has to heal"

Unfortunately, few participants continued to have contact with health care professionals while the patient was waiting for access to rehabilitation services.

Although participants did not feel as compelled to tell their story repeatedly during this phase, they continued to confide in others about their fears and hopes. Participants who had good pre-trauma relationships with others in their lives were able to confide and work through trauma-related thoughts and emotions with their assistance. In contrast to Phase II, they limited their social network to include those close to them who were part of their everyday life as opposed to reaching out to those from the outside who offered assistance. Moreover, the confiding relationships became more intense. Marilyn recounted how her friend had appreciated how she had not kept her feelings "behind closed doors" and described how being open with her friend enabled her to work with her pain. She said, "I've been really really open. She said that it's made a big difference. Even though it's been painful, I've been working with the thoughts and feelings." As well, because Marilyn was willing to trust and confide in close others, it made it easier for others to support her. She said, "So people don't feel like they have to walk on cracked eggs sort of thing? That it's OK to say something, it's OK." As such, it made it possible for others to accompany her on her healing journey.

Participants who did not have close relationships with others in their lives also continued to seek validation of their perception of the patient's deficits and progress. However they avoided confiding in others who were part of their everyday life and continued to reach out to people on the outside of their social network. They felt safer confiding in people who were not connected emotionally to their situation. For example, Lise said, "I talked to some people in [town] and I guess they validated my feelings you know like Geez I wasn't crazy to have a problem with all this you know? I had reason to be upset." In addition, she reached out to counselling services in her community but was faced with a waiting list. She said, "I saw the intake psychologist about a month ago and she said it could be a month. I guess that's not bad (laugh)... It's just that I need help to think straight for myself, think clearly for myself." Because participants such as Lise had a tendency to reach out for more distant confiding resources, they may potentially have been placed at risk by interruptions in the continuity of the patient's care. This pattern was also true for other participants who had difficult relationships with others in their lives. However, many were creative in finding resources that would validate their experience. For example, Carol described how she found validation for her son's behaviour in the newspaper. She said, "Actually I saw this thing in the Sun about a study they are doing on people who are obsessively worried about things... I saw that and thought, Gee, that's [my son]! You know, he was kind of that way?"

In summary, during this phase, participants continued to work on trauma-related thoughts and emotions by accessing close others to validate and reframe their perception of the patient's progress and of the impact on their everyday life. This was also true for those who did not have close relationships with others in their lives although they had to work a little harder at locating resources. However, they continued to reach broadly in their support network to find safe confiding resources. As a result, a lack of accessibility to health care professionals may have been more detrimental for these participants than for those who could readily confide in others in their everyday lives. However, these participants were quite creative in finding resources to assist them in continuing their work on trauma-related thoughts and feelings such as articles in newspapers, magazines, newspapers, and the Internet.

Assessing the Self

During this phase, participants continued to compare and evaluate their reactions, and how they had managed with the traumatic event. As seen in Phase II, participants continued to see their coping in a favourable light and to be surprised by their coping strength. For example, Cheryl said, "Now that I look back, I can't believe that I've coped as well as I did... I still worked part-time, and I drove everyday to that hospital and, managed the cheques for the business, gave the bookkeeper heck (laugh) and did all this." These feelings were further validated and reinforced by close others. Cheryl added, "Our youngest son said, 'You know, you're really tough... I didn't realize you were so tough!'" Such comments helped to reinforce a positive concept of self. Participants also compared their current reactions to how they had handled past traumatic events. Even when their perception of self had not been positive, they tended to focus on how their coping had been stronger this time around. Beverly described her reactions to her first head-injured son's injuries. She said, "I didn't deal with it at all. I let it go by me! I don't remember much, I was numb." She then added how she wanted to be there for her son this time. She said, "I feel like now I might be stronger. I have to be stronger; I have to be strong... It's kind of hard to feel that confident but it feels good."

In addition, during this phase, participants became acutely aware that if they were going to be strong for the patient, they needed to begin to balance their own needs with the patients', and to find time for themselves. Cheryl recalls her response to her husband's request to accompany her to the shopping mall. She said, "You can if you want but I didn't really want you to (laugh). I just really needed some time to myself." He said "Oh! OK, I'm fine here". So I had a couple of hours to myself." She had observed that her husband's anxiety and poor concentration were worse in public places and this made her feel frustrated. She recalled saying to her husband, "I find you kind of stressful and I just needed some time by myself" and he said "Oh, Ok". (laugh)." Women who had a strong pre-trauma relationship with the patient and a positive sense of self seemed able to define the boundaries between their needs and their husband's. In contrast, Lise, who did not have a good pre-trauma relationship with her husband, recalled how she responded to her husband's request to accompany her to the grocery

store. She said that her husband made her feel tense and that she wanted to do this on her own. She was remorseful that she had not been able to clearly communicate her need to her husband and felt bad about her decision not to take him shopping in the end. She also struggled in balancing their mutual needs. She added, "I don't want to make him feel more depressed, but I got to figure out when to look after me and when to look after him."

In summary, participants continued to compare and evaluate their reactions and how they had managed to deal with the traumatic event in the context of how they had coped with past traumatic events. They tended to see themselves as stronger than most people in similar stressful situations and to view their own coping strength in a favourable light. Furthermore, other people in their lives reinforced their appraisal of self. Even when their self-perception had not been entirely positive pre-trauma, participants tended to make positive comments about their coping strength. These positive self-evaluations contributed to maintaining or re-establishing their values and beliefs about the self. During this phase, participants were conscious of the importance of balancing their needs with the patient's if they were going to be able to sustain their coping strength. This was more difficult for participants who did not have good pre-trauma relationship with the patient.

Evaluating the Impact of the Event on Everyday Life

As illustrated on Figure 4, participants continued to evaluate the event. However, most participants no longer had a need to focus on causal explanations for the event and the need to reflect and talk about the event had decreased dramatically. As Cheryl said, "I'm not doing that so much anymore." For a few participants though, these cognitive efforts continued which may have indicated more difficulty in finding a fit between the event and prior conceptualizations of the world and their lives. For example, Beverly said, "Why is this happening to us? Why is it? ... Why [my son] you know? Why is it happening to us you know?" She continued to focus on issues of justice and fairness and at the same time, she purposefully worked at avoiding her trauma-related thoughts. She said, "That's what I'm thinking all day long, but at night time? I was thanking Him for it happening, right? I say, 'I can't dwell on why' ... Then [the next day] it all comes back,

the same thing.” She had described similar reactions to other life trauma with which she had been struggling. Furthermore, Beverly had learned to compartmentalize her experience later than other participants in the post-trauma phase, and unlike most other participants she continued to do so well into Phase III. She said, “I’m telling myself now can’t think of yesterday, I think of today. And it’s doing just one day at the time... You can’t deal with everything.” These findings suggest continued cognitive work in reconciling trauma-related thoughts and emotions with her values and beliefs about the world.

Even though a few participants such as Beverly continued to work on trauma-related thoughts in relation to their values and beliefs about the world, all participants began to evaluate the event in the context of how the event and the patient’s injuries affected their everyday lives and their life goals. The patient’s ability to function in everyday life and the resulting changes in their relationship began to raise concerns for the future. Cheryl reflected on the changes in her husband’s personality. She recounted:

[My husband] used to try and step on my toes, whereas now, he lets me be the boss? (laugh)... The time is going to come where I’m gonna want him to start making some decisions. But, right now, I’m making all the decisions.

Despite her concern about the long-term impact of changes in their relationship, she saw benefits resulting from some of the changes in her husband and she left room for possible improvement in his condition. Similarly, Beverly was also able to begin to focus how the accident potentially affected her life goals, even though she continued to use questioning and compartmentalizing during this phase. She recalled having the following thoughts:

Our custom is when a mother or father gets old, native people usually take care of their parents. They take in their parents... I don’t know yet if this will happen... It depends how well he’s going to be. He’s not as bad as (other head-injured son) so he might be better, right now he seems pretty good.

Although Beverly recognized that her life might be on a different course, she continued to leave room for her son to eventually recover. This was the case for all of the participants. While they recognize the possibility that life could be changed forever, they continued to believe that the patient could recover fully. One strategy that helped participants in maintaining their focus on the possibility of recovery was that they began

to look for examples of how others had survived bad accidents and done well. Cheryl described her reactions when a young girl at the barbershop told her about her father's recovery from a fall 10 years previously. Cheryl had been unable to tolerate such stories during Phase I and when this was pointed out to her she said "Oh really? I don't remember. That IS interesting". An explanation for this change might be that because she now began to entertain the possibility of long-term effects on their life, she had a need to balance her concerns with success stories.

Despite being a little more realistic in terms of the possible impact of the patient's injuries on their relationship and on their lives, participants continued to reflect on the positive aspect their experience. For example, Marilyn said: "I would not invite this but once you're involved in it, there's a lot to be enjoyed." Participants also began to express how the event had given them a new perspective on life. Some felt that they were given a new opportunity. Other participants felt that this traumatic event gave them an opportunity to make a difference. Other participants re-discovered past beliefs. Cheryl said:

I was brought up in quite a religious family and [my husband] doesn't have a religious bone in his body. So I've sort of let that drop... How you were brought up and the beliefs that you've had, they all come back. It was important in my coping. I think how you cope is who you are.

Many of the participants also reflected on how their priorities had changed as a result of the traumatic event. For example, Cathy said, "It has changed my perception of things a lot... We do take an awful lot for granted... You know, life is precious and you realize it when you go through something like this." All of the participants reported appreciating life in a different way and they remained focused on the positive aspects of how the event had changed their outlook on life. As Christine said: "I mean it's not easy and it makes you realize a few things you know, like everyday there are good things." These beliefs appeared to help participants to re-establish or maintain a positive outlook on how they viewed their world and their lives more specifically.

In summary, participants continued to evaluate the event but most no longer had a need to talk about the traumatic event and to focus on causal explanations. Those few participants who did need to discuss the event appeared to have more difficulty

reconciling their trauma-related thoughts and emotions with their values and beliefs. Despite ongoing cognitive processing, they were also able to focus on evaluating the impact of the event in the context of their everyday lives. All participants began to express concern for the long term although these thoughts were tempered by using uncertainty to fuel a possible positive future. They began to actively search for examples of success stories to validate their hopes. During this phase, participants also began to focus on ways in which the traumatic event had positively changed their lives and they began to describe a new perspective on their lives. As such, they continued to maintain a positive interpretation of how they viewed their lives and goals as a result of the traumatic event.

Summary: Phase III

This phase began once the patient was first re-introduced to the home environment either by being discharged home or by going home on pass from the hospital or rehabilitation centre. Once participants could observe the patient in the context of everyday life, they began to more accurately evaluate the full extent of his deficits and recovery. Although they found comfort in seeing the re-emergence of the patient's past characteristics and life patterns, they were also able to notice more subtle deficits that affected their ability to resume everyday life. Although they did not give up hope for significant improvement, they began to realize the need to be more realistic about their expectations. They worried about the patient's safety and felt protective of the patient in public situations.

During this phase, participants continued to compare and evaluate pre- and post-trauma relationships and support. Although they had resumed their roles and responsibilities at this point, they continued to accept and mobilize the help of others to keep the home and work place functioning and to keep the patient safe. However, at the same time, participants tended to limit their exposure to the social network in order to conserve energy and protect the patient from the reaction of outsiders. At this time, participants also began to evaluate how their relationship with the patient had changed as a result of the patient's injuries. In addition, they recognized that these changes in the relationship affected the whole family therefore necessitating a re-negotiation of roles

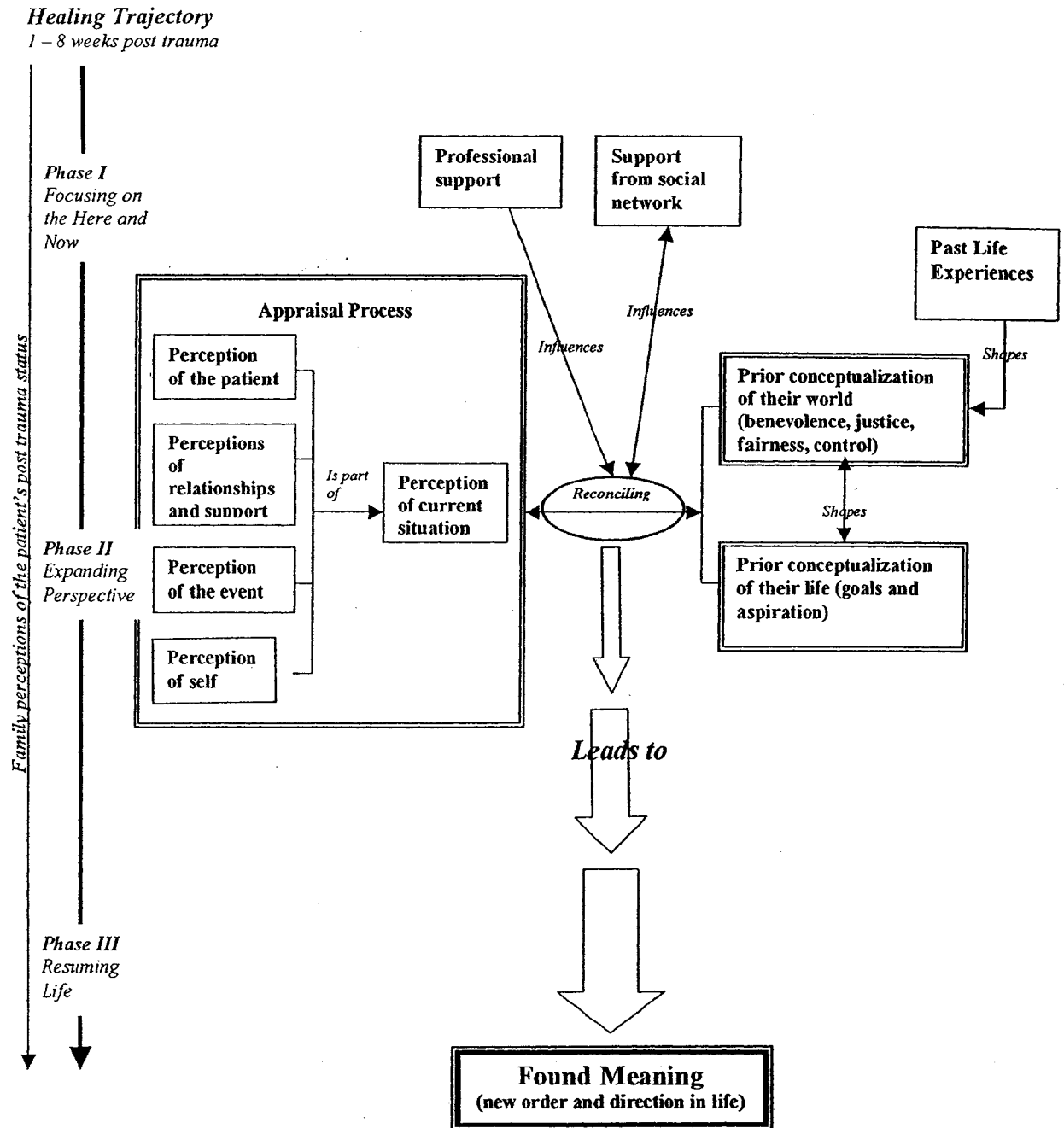
and relationships in the family. As seen in Phase II the quality of the pre-trauma relationship with the patient was an important determinant of the participants' ability to work with and commit to the patient. Those who had experienced difficult relationships became further stressed by the changes in the patient. As seen in Phases I and II, the support of others was important in helping participants validate and reframe their perception of the patient's progress and its impact on everyday life. However, they tended to restrict their confiding activities to family and close friends. Participants who did not have close relationships with others also found resources to validate and re-frame their perceptions of the patient's progress and recovery. They tended to avoid the risk of confiding in people who were part of their everyday lives and to reach more broadly in their support network. Unfortunately, most of the participants had lost contact with health care professionals at this point, mostly due to a lack of access to rehabilitation services. As a result, this source of validation and re-framing was absent and those participants who needed to reach out for this assistance may have been more adversely affected.

At this time, participants also continued to evaluate how they had managed to deal with the traumatic event in the context of how they had coped with traumatic life experiences in the past. They tended to see themselves as coping better than the average person, which was reinforced by comments made by others. Even when pre-trauma self-perceptions had not been entirely positive, participants tended to make positive self-evaluations. One difference from Phase II was that participants began to acknowledge a need to balance their needs with the patient's if they were going to be able to sustain their coping strength. This was more difficult for participants who did not have a good pre-trauma relationship with the patient.

In addition to maintaining or re-establishing a positive sense of self, participants continued to evaluate the event in the context of their values and belief system. However, unlike Phases I and II, most participants no longer had a need to talk about the event repeatedly and to focus on causal questioning. Those that did seemed to have greater difficulty in working through trauma-related thoughts and emotions. The focus of examining the event during this phase was in relation to how it affected their way of being in their everyday lives. All participants began to express concern for the long term,

although these thoughts were tempered by the possibility of a preferred future. As such, they began to seek examples of success stories. Participants also began to focus on ways in which the traumatic event had positively changed their lives and how their perspective on their lives had been transformed. This cognitive work helped them to maintain or re-establish a positive bias in the values and beliefs that guided their everyday life.

Figure 5 - Finding Meaning in the Aftermath of a Head Injury



Finding Meaning in the Aftermath of a Head Injury: The Grounded Theory

Three distinct phases were identified during the early phase of recovery with an evolving process of finding meaning embedded within each phase. First, the characteristics of each phase will be described. The process of finding meaning and the relationships among variables will then be described as illustrated on Figure 5. Transitions in the process of finding meaning over the three phases will also be discussed under each core variable of the process.

The Phases

The three phases identified in the process of finding meaning were called “Focusing on the Here and Now”, “Expanding Perspective”, and “Resuming Life”. The transition between these phases was triggered by the participants’ own perception of improvement in the patient’s status as opposed to that of health care professionals or a move from one level of care to another. Their perceptions fluctuated with the ups and downs of the patient’s level of consciousness and as such, they joined the client on a mutual journey of recovery. During the first phase, participants experienced a period of initial clarity and action, followed by a variety of emotions and physical responses, and progressive difficulties in concentrating and thinking clearly. The notion of time and place became blurred and they began to compartmentalize their experience and focus on the “Here and Now” in the ICU/neuro ICU. They focused on whether the patient was going to survive his or her injuries and adopted a “Wait and See” stance. During this time, they needed to be in close physical contact with their head-injured relative and they were watchful for any sign that the patient was “waking up”. Although they wanted information about the patient’s injuries and the treatment plan and goals, they did not want to hear about the patient’s prognosis at this time. They were focused on the patient and relied on offers of assistance from their social network to maintain life on the outside. Once the patient’s level of consciousness began to improve and participants felt that the patient was going to live, they began feel ready to look outward. Phase II was characterized by a marked decrease in their need to compartmentalize and a beginning consideration of what the traumatic event, and more specifically the patient’s condition,

might mean in the context of their lives. As a result, they became interested in hearing information about the patient's prognosis. Participants continued to feel compelled to be with the patient at the hospital and began to work and re-connect with the patient as his or her condition improved. They focused on the patient's progress fuelled by the possibility that the patient could return to "normal". Although most of the participants began to attend to life outside the hospital, they continued to accept assistance from others. In addition, they began to mobilize support from others to help them attend to other responsibilities in their lives so that they could continue to be with the patient. The transition to the third phase occurred when the patient was able to have contact with his or her everyday life, usually in the home environment. For some it meant being discharged home whereas for others, it meant being able to go home on pass. As they began to "Resume Life", participants began to realize the full impact of the patient's deficits on everyday life and to entertain the idea that their lives might be permanently altered. As such, they adjusted their expectations of the patient, of roles and relationships in the family, and of their life goals. At the same time, these thoughts were tempered with a continued belief that a positive outcome was still possible. During this phase, participants resumed their roles and responsibilities more fully and consequently, they adjusted their need for support from others. They continued to feel protective of the patient and as a result, they resumed life in a careful and measured way.

The Process of Finding Meaning

As illustrated in Figure 5, the process of finding meaning was ongoing and embedded within each phase. This process was characterized by an emerging fit between the participants' perception of their current situation and their pre-trauma value and belief system. As these perceptions were reconciled, they began to find new ways of thinking about their world and their lives. That is, they began to find new meanings. This process was continuous over time: as participants engaged in this cognitive and emotional process, new meanings began to emerge. Although continuous, the process was not linear as it unfolded, influenced by the dynamics of the participant's and the patient's mutual journey. As such it might best be represented as an upward spiral over time.

Participants' Perception of their Current Situation

A number of interrelated appraisals informed the participants' perception of their current situation. These involved perceptions of the patient, of the traumatic event, of the self, and of relationships and support. Over time, some of these appraisals were more in the forefront than others, and processing activities that informed perceptions shifted in nature from data gathering to evaluation of the different aspects of their situation.

More than any other source of data over the three phases, the participants' observations of the patient were central in shaping their perception of their current situation. Initially, they observed the patient for any signs of improvement guided by their unique "knowing" of the patient's pre-trauma characteristics. Being physically present at the bedside facilitated this work. They focused on information that would support their need to believe that the patient could survive his or her injuries and they were troubled by negative information about the patient's prognosis. As the patient began to improve, participants began to seek information actively that would help them to anticipate the patient's progress and how it would impact their lives. They monitored the patient's post-trauma status and behaviours and they were watchful for the emergence of the patient's pre-trauma characteristics. They focused on evidence of the patient's progress to maintain a belief that full recovery was possible. Once they were able to observe and work with the patient in their pre-trauma life context, participants continued to monitor the patient's post-trauma behaviour and they began to evaluate the impact of his or her deficits on everyday life. While they continued to believe that a good outcome was possible, they began to consider that their lives might be altered as a result of the changes in the patient. At this point they re-adjusted their expectations of the patient's recovery and roles and responsibilities within the family, at least temporarily. Across the three phases, the participant's ability to gauge the patient's condition was partly influenced by the quality of their pre-trauma relationship with him or her. Those who did not have a close relationship had difficulty tolerating being at the bedside in order to perceive subtle cues about the patient's progress. As a result they relied heavily on information provided by health care professionals and became quite distraught by negative information. They also found it difficult to commit to working with the patient. This meant that they had fewer opportunities to observe the patient and to gather the data

necessary to draw conclusions about the impact of the event on their lives. These difficulties were compounded by a lack of information from health care professionals during Phases II and III. As a result, these participants remained anxious about their situation.

Also informing the perception of the participants' current situation was their perception of the traumatic event. Initially, they gathered information about the details of the accident from a variety of sources in an attempt to re-construct the causal nature of the event and its outcomes. Among the study participants, events such as assault caused more distress than other types of accidents. Moreover, the participants' understanding of the resulting injuries to the patient also influenced their perception of the impact of the event on their current situation. As the patient improved, participants became more focused on appraising the event in terms of its effect on their lives and as they returned to their home environment with the patient, they began to evaluate the event in relation to its impact on their everyday lives and life goals. Although appraisal of the event continued to inform the participants' perception of their situation throughout the three phases, the details of the traumatic event became less important to them over time. In fact, they began to focus more broadly on the event and how they had benefited and been transformed by this occurrence in their lives.

The support that participants received from others also shaped how they perceived their current situation. Feeling the concern and support of others in their lives, including health care professionals and strangers, made them feel better about their situation. It also helped them to place the accident in the context of a benevolent world and to value family and friendship. In contrast, a lack of quality relationships with others made participants feel anxious and alone in dealing with the situation. During this time, participants also appraised their relationships with the patient. The more positive the pre-trauma relationship, the more positively they perceived the current situation. The evaluation of their relationships and support continued throughout the three phases.

The participants' appraisal of their own reactions to the traumatic event and how they had managed as a result also shaped their perception of the event. This type of appraisal did not begin until phase II although they also considered retrospective data in informing perceptions. All of the participants, including those who reported not having

been strong in dealing with past traumatic events in their lives, described themselves as coping better than they had expected and better than other people in similar situations. These appraisals affected their perception of their situations by giving them energy to endure.

Reviewing Prior Conceptualizations

As the participants' appraisals informed perceptions of their current situation, they began to review how they had conceptualized their world prior to the traumatic event in their lives. More specifically, depending on how much these had been undermined by the traumatic event, they began to deconstruct their values and beliefs about benevolence, justice, fairness, and control. These basic beliefs had provided a sense of direction and order in their lives, and shaped their life goals. Because these informed each other over time, a bi-directional arrow was used on Figure 5. As well, the participants' value and belief system was influenced by past life experiences, including past traumatic experiences. Participants who had experienced other negative events had re-adjusted their values and belief systems such that it could more easily encompass other traumatic events. Although these participants' value and belief systems tended to be positive, it was perhaps less so than those who had not experienced prior traumatic events.

As participants appraised their situation and reviewed their prior values and beliefs, they began to work at reconciling these perceptions so that they could find a comfortable fit between them. They did this by engaging in a back and forth process of comparing, reflecting, questioning, and story telling. This is illustrated as a bi-directional arrow on Figure 5. This process began during the early post-trauma phase and continued over time. Initially, the participants focused on more general conceptualizations of benevolence, justice, fairness, and control. Some of the participants reconciled these two sets of perceptions more easily than others. It seemed that if the person had experienced previous traumatic events she could more easily encompass the current traumatic event. However, if a person had not resolved previous traumatic events, she had difficulty processing the current event and the effect appeared to be cumulative. Another consideration as to the ease of finding a fit between current and past conceptualization

was the person's perception of the event. Some types of traumatic events seemed to be more difficult to reconcile than others. For example, participants whose loved one had been injured as a result of an assault continued to work on reconciling the event well into phase III. Generally however, most of the participants described a marked decrease in their need to talk about the event and they became less concerned about issues of causality, suggesting that they had successfully moved in the direction of working through the event in the context of their values and beliefs about the world. During phases II and III however, they began to explore more actively how the event fitted into the context of their lives and more specifically in relation to their life goals and aspirations. They focused on how the patient's progress and changing relationships affected their everyday lives.

Support from Others

In addition to the person's appraisal of relationships and support in informing the perception of the situation, support also emerged as a mediator in the process of reconciling the person's perception of the situation with prior conceptualizations. For most of the participants, others in their support network facilitated these cognitive and emotional efforts by validating their perceptions and experiences. In addition, when the relationship was close, others also helped the participants to re-frame their trauma-related thoughts and emotions. Over time, their confiding activities became more focused to those close to them. In contrast, when participants had experienced negative relationships with those in their support network, they avoided validation and re-framing opportunities. In fact, some of the participants described the experience of receiving feedback from others in their lives that had been detrimental to their ability to work through their situation. Furthermore, they often could not tolerate each other's trauma-related thoughts and emotions. As a result, they found it risky to confide in people who were part of their everyday lives, and they felt safer confiding in strangers, including health care professionals. During phases II and III, they began to search for resources that were removed from their everyday lives in order to support their cognitive efforts.

Although health care professionals emerged as a potentially important source of support during the first two phases of recovery (there is a lack of data about Phase III due

to the participants' lack of access to professionals), it became evident that participants held different expectations from these relationships as compared to those in their social network. Participants looked to health care professionals for informational support and for validation of their observations of the patient's post-trauma status and progress. In turn, this helped their work of working through trauma-related thoughts and emotions. However, they were rarely described by participants as helpful in helping them to reframe the event in the context of their values and beliefs about their world and their lives. The relationships tended to be unidirectional and time limited. The sheer number of professionals with whom the participants had contact further exacerbated this. Moreover, a lack of consistent caregivers during phase II and a complete disconnection with the health care system in phase III made it impossible for participants to develop trusting relationships that would enhance this depth of cognitive work. This situation may have been more detrimental for participants who did not feel safe in confiding and working through trauma-related thoughts and emotions with people in their everyday lives, and who were looking outward for such resources.

Found Meaning

As participants moved from phase to phase, they began to reconcile their situation with their prior conceptualisations and what it meant in relation to their lives. All of the participants began to report progress in coming to terms with their situation. As they worked through their trauma-related thoughts, they reported regaining a sense of stability and order in how they made sense of their world and of their lives. They began to review life goals and expectations and many described finding a new perspective in their lives. Quantitative data supported these findings in that over time, there was a decrease in the participants' emotional distress score as measured by the Brief Symptoms Inventory, and a decrease in Intrusion and Avoidance scores on the Impact of Event Scale, which measured cognitive processing. For some of the participants, regaining a sense of meaning was more work than for others. It seemed to depend on how much their core beliefs and values about the world had been compromised by the event, and whether they had resolved traumatic life experiences prior to the accident. The core and process variables in this emerging grounded theory suggest important factors to be considered in

the early identification of mothers and wives at risk, and in the development of nursing interventions that facilitate adjustment during the early phase of recovery.

CHAPTER 5 – DISCUSSION

This study examined the process of finding meaning by mothers and wives of the head-injured during the early phase of recovery. During this time, a complex process involving a perception of the current situation in the context of prior conceptualizations of the world and of life evolved over three distinct phases. A new sense of order and direction in life began to emerge as participants engaged in these cognitive efforts over time. This process was mediated in part by social and professional support.

In consideration of the study findings, the discussion will be organized according to the elements of a paradigm (Strauss & Corbin, 1998): conditions, psychological responses, and consequences. The study findings will be compared to the literature and theoretical models reviewed earlier. Additional literature accessed through constant comparative techniques (Glaser & Strauss, 1967; Strauss & Corbin, 1997) will also be outlined. This will be followed by a discussion on the limitations of the study and implications of the findings as they relate to theory, nursing practice and research. The chapter will conclude with a brief summary of the study's major contributions.

Conditions Associated with the Traumatic Event

In keeping with the American Psychological Association's definition of traumatic events (1994), the unexpected head injury of a family member caused the whole family intense fear for the survival of their relative and a profound sense of helplessness relative to the eventual consequences of the patient's injuries. Three types of conditions previously reviewed shaped the participants' responses to the traumatic event. These were causal conditions, intervening conditions, and contextual conditions.

Causal Conditions

Unexpected events such as the head injury of a family member are considered causal conditions that must be responded to by the person. To date, most trauma studies have sampled participants who had experienced a variety of trauma situations without

defining and examining the nature of the trauma event itself (Frutiger et al., 1991; Glancy et al., 1992; Grossman, 1995; MacKenzie et al., 1987; Shalev et al., 1996; Van Dongen et al., 1993). The results of this study have shown that the nature of the event influenced the participants' perception of the event. For example, injuries that resulted from an assault more seriously undermined the person's prior conceptualizations of the world compared to accidental injuries. As a result, these participants continued to engage in causal questioning, story telling, and compartmentalizing of their experience as they worked through trauma-related thoughts and emotions. These findings therefore suggest that the nature of the event will need to be considered in future trauma studies. The traumatized patient's condition also influenced the participants' responses to the traumatic event. In fact, the participants' appraisal of the patient's condition was central in shaping their perception of the event and of the situation. Their response to the traumatic event fluctuated in concert with the patient's changing level of consciousness and progress. The patient's status prompted transitions across the three phases identified during the post-trauma period. It is therefore important to consider the participants' perceptions of the patient's condition in future studies. Moreover, these findings provide support for the foundational assertion in the McGill Model of Nursing (Gottlieb & Rowat, 1987) that a traumatic event affects the whole family system. As a result, future studies will need to consider individual as well as family system perspectives and their relationships and interactions.

Intervening Conditions

Two intervening conditions have emerged as important in shaping the participants' psychological responses and therefore the consequences of the traumatic event. These were past experiences with negative events and the quality of their social relationships. Other intervening conditions previously discussed such as the participants' education, occupation, and income, did not emerge as central in shaping the participants' psychological responses in this study and require further study.

The study findings suggest that the participants' past traumatic experiences shaped their conceptualizations of their world and of their lives. As a result, this made room for the integration of the new traumatic event and the participants were able to

more easily work through trauma-related thoughts and emotions. In a sense, past experiences provided a reality check against which to judge perceptions of the current traumatic event. This is contrary to findings in the general trauma literature that major pre-trauma life events were negatively associated with psychological adjustment (Grossman, 1995; Ruch et al., 1980; McFarlane, 1988a). However, the study findings also showed that when a participant had not resolved past traumatic experiences, she had more difficulty in working through the current situation and in fact their stories suggested a cumulative impact. This was substantiated by quantitative measures of emotional distress and cognitive processing. Together, these findings are consistent with cognitive processing theory (Horowitz, 1986; Janoff-Bulman 1992), which recognizes the importance of past experiences in shaping a person's cognitive schema to assimilate or accommodate a person's subsequent life experiences. If a person has not modified his or her schema in light of past traumatic experiences, or if the schema was modified negatively, it stands to reason that they would have difficulty incorporating a new traumatic event into their cognitive schema. The above findings are also consistent with recent literature about the concept of uncertainty (Penrod, 2001), which proposes that past experiences contribute to a person's ability to assign probability for outcomes. This in turn informs the person's perception of uncertainty by helping them to forecast the future and hence contributes to shaping their perception of the current situation. If a person had previously been able to reach a successful outcome from a traumatic incident he or she would be more likely to expect the same. Even if there is uncertainty, there is hope for a positive outcome. Given the study findings and theoretical support, it is important to consider the qualitative impact of the participants' past life experiences in the context of a negative life experience such as a brain injury.

The quality of the participants' pre-trauma relationships also emerged as important in shaping their responses and therefore consequences of the traumatic event. In keeping with convergent evidence from the support literature (For reviews, see: House et al., 1988; Thoits, 1995) and the head injury literature (Florian et al., 1991; Martin, 1988; Resnick, 1983; Rivara et al., 1992), poor pre-trauma relationships with close others led to a continued pattern of poor relationships post-trauma and difficulties in processing trauma-related thoughts and emotions. These participants found it more difficult to

accept and mobilize support from others, and the relationships tended to become more difficult. Moreover, the study findings also showed that a poor pre-trauma relationship with the patient made it more difficult for the participants to “be with” and “work with” the patient. As a result, they had difficulty assessing the patient’s condition and in reconnecting with him or her. These participants also tended to be distressed by the patient’s post-trauma behaviour and were frustrated by the uncertainty of the patient’s prognosis. These results are in keeping with the one study located that examined the relationship between past marital adjustment and post-trauma responses (Robinson, 1990). It is also consistent with studies that have shown the quality of the marital relationships to make a unique contribution to a person’s mental health (Gove et al., 1983; Thoits, 1982; Lieberman, 1982). These findings suggest that future research needs to consider the quality of the pre-trauma relationship.

Contextual Conditions

Two contextual conditions have emerged in the data as important influences of the participants’ psychological response. First, participants expressed a compelling need to be physically present at the patient’s side in the ICU/neuro ICU and unit. Nursing’s recognition of the importance of family needs and presence when a relative is hospitalized is evident in the literature (Bernstein, 1990; Burke, Kauffman, Costello, & Dillon, 1991; Daley, 1984; Hampe, 1975; Holden, Harrison, & Johnson, 2002; Kleinpell & Powers, 1992; Koller, 1991; Molter, 1979; Robinson, 1987; Stillwell, 1984) and has been the impetus for a shift in visiting policies over the past 30 years. During the first phase, it was important for participants to be physically present at the bedside as it enabled them to assess the patient and the significance of the traumatic event. A few recent studies have begun to examine the interactions between the patient, the family and health care professionals in critical care units (Carr & Clarke, 1997; Hupcey, 1998, 1999; Jamerson, Scheibmeir, Bott, Hinton, & Cobb, 1996; Plowfield, 1999). The role of the family as “observer” has emerged as important in these studies and although a few have also reported that family members search for meaning while waiting for the patient to improve (Plowfield, 1999), none of the studies have described how observing the patient contributes to the process of finding meaning. Being physically with the patient was also

important in phases II and III as it enabled participants to work with the patient, to monitor progress, and to work through trauma-related thoughts and emotions. No studies were located that examined the concept of observing the patient beyond the critical care unit. A number of factors were reported by participants as interfering with their ability to be at the bedside. First, participants were upset when their access to the patient was limited due to visiting policies. Although there has been a trend towards enabling family members to be present at the bedside, a few authors report inconsistencies in this practice as a result of nurses controlling access to the patient (Hupcey, 1998; Plowfield, 1999). A second factor interfering with participants' ability to be at the bedside with the patient was related to their need to attend to "life on the outside". This was intensified if participants were not comfortable accepting and mobilizing assistance from others in their network. A few studies were located that described the internal conflict experienced by family members that could not be present at the bedside (Hupcey, 1998, 1999; Hupcey & Penrod, 2000; Walters, 1995). However, none of these studies examined the role of social support in enabling family members to be present at the bedside. A third factor related to the participants' ability to be at the bedside related to the quality of the pre-trauma relationship with the patient. Those who had poor relationships had difficulty "being with" the patient and were less perceptive of subtle cues in the patient's condition. No studies were found that addressed this finding. Overall, because the participants' perception of the situation was grounded by their assessment of the patient's condition and progress, an inability to be at the bedside seriously undermined their ability to engage in the cognitive work of healing.

Access to information emerged in the data as a second contextual condition important in influencing the participants' psychological response was access information. The need to have questions answered and to have information about the patient's condition has been consistently identified as one of the most important needs of family members of the critically injured patient (Daley, 1984; Davis-Martin, 1994; Freichels 1991; Leske, 1986, 1992). These studies were based on Molter's (1979) classification of the 45 potential needs of an ICU family. However, these studies have been carried out in terms of the family members' global needs, usually at one point in time during the first three days after the patients' admission to the ICU. In a recent review by Sinnakaruppan

and Williams (2001), the majority of the caregivers of head-injured adults identified a need for information as one of their most important needs. Only one study was found that clarified the goal of information seeking behaviours (Jamerson et al., 1996). In this study, information seeking was described as a tactic used both to move out of the hovering state and to identify the patients' progress. Similarly, the findings of this study suggest that the participants primarily collect information in order to inform their perception of the patient's status and progress. However, findings have also shown that the nature of information required by participants varied over time. Initially, they need information about the event, the extent of the patient's injuries and the treatment plans and goals. However, as the patient stabilizes and the family member believes that the patient may survive his or her injuries, they begin to search for information about the patient's prognosis and how they can best assist with the patient's recovery. One factor influencing the participants' access to information was the availability of health care professionals and the quality of their relationship with the family. Study findings showed that while the patient was in the ICU, information was mostly available. However, professionals tended to include information about the patient's prognosis, which the family was not willing to consider during the early phase. As well, health care professionals were perceived to maintain a "distance" from the family's experience, which further limited access to information. Once the patient was moved to the step-down or neuroscience unit, there were breaks in the flow of information and the family member did not readily have access to needed information. A few studies have addressed the emotional distancing of nurses that occurs as a result of their need to balance looking out for the patient and for themselves (Chesla & Stannard, 1997; Hills & Hupcey, 1998; Hupcey, 1999). Hupcey (1998) found that the nurses felt overwhelmed, tired or busy with an unstable patient as reasons for being short with a patient's family, and felt justified in limiting visiting times or not answering questions in detail. Consistent with these findings, the participants in the current study often reported nurses as being too busy to pay attention to family members. Overall, the study findings suggest that a lack of access to appropriate information and to health care professionals interfered with the participants' cognitive work.

Although the relationship of the participant to the patient as a mother or a wife was identified in the head injury literature as a potentially significant contextual condition, no significant differences in their experience emerged from the study data. In fact, mothers who were single or who had poor relationships with their spouse had equally difficult situations to contend with as compared to wives who lost the patient's financial support or as a confidant. It may be that differences in adjustment emerge later in the post-trauma period. Perlez, Kinsella, and Crowe (2002) reported that wives were at greater risk of poor psychological outcomes 19 months following their relatives head injury compared to mothers. In that study, 79% of wives reported having to assume much more responsibility than prior to the accident compared to 46% of mothers experiencing this change. Wives were also significantly angrier and less satisfied with their family life than were mothers. In contrast, a review of needs studies involving family members of the head-injured reported mixed findings in relation to differences in unmet needs of mothers and wives (Sinnakarupan & Williams, 2001). Gender may also contribute to the adjustment of family members. The results of a meta-analysis of coping behaviours of men and women found women to be more likely than men to use strategies that involved verbal expression to self (rumination, positive self-talk) and verbal expressions to others (seeking emotional support) (Tamres, Janicki, & Helgeson, 2002). Women were also found to appraise stressors as more severe compared to men. Gender differences were also found in relation to the buffering effects of life meaning in a study of men and women with suicidal manifestations (Edwards & Holden, 2001). However, this area has remained relatively unexplored to date in the head-injury literature. Together, these findings suggest the need to consider more carefully the unique context of each participant over time, in relation to the perception of his or her situation and sense of meaning.

Psychological Responses to the Traumatic Event

Although cognitive processing was initially reviewed as a consequence of the process of finding meaning, study findings showed that it is central to the person's psychological responses to the traumatic event. More specifically, the findings of the study demonstrated a pattern of reconciling the participants' appraisal of their current

situation with their past conceptualizations of their world and of their lives. These findings are similar to cognitive processing theory as described by Horowitz (1986) and Janoff-Bulman (1992). According to these authors, a person's cognitive schema represents their most basic assumptions about the world and their place in it. When a traumatic event occurs in people's lives, they attempt to assimilate traumatic events in their cognitive schema. When the traumatic event is incongruent with the person's most basic world assumptions, cognitive efforts are aimed at reconstructing the schema. Janoff-Bulman (1992) further notes that cognitive processing is biased towards assimilation rather than accommodation suggesting that people have a need to interpret information in a schema-consistent manner. Horowitz (1986) had proposed that as the person's mind engages in this cognitive work, he or she experiences intrusion and avoidance reactions. The findings of this study are consistent with these theoretical assertions. However, these authors fall short of explaining how this process occurs. The findings of the study extend this theoretical knowledge by showing how the women's perception of their situation provides the stimulus for the cognitive work to occur. Their perception is shaped by a complex set of interrelated appraisals of the patient, of the event, of their relationships with others, and of the self. Moreover, the participants' perceptions of the subtle re-emergence of pre-trauma patient characteristics formed the basis for their perception of the recovery situation. These findings are in keeping with the work of Folkman, Lazarus, Gruen, and Delongis (1986) on coping which places appraisal of the event as central to determining the patient's coping efforts. However, the findings of this study extend this work by outlining the types of appraisals carried out by family members during the early phase of recovery. Furthermore, it has shown that family members' perceptions are not only limited to the event but rather to their entire situation which includes the specific context of their lives.

As outlined by Horowitz (1986), the person gradually works through trauma-related thoughts and emotions at his or her own pace by using intrusive and avoidance reactions. Evident in this study was the finding that intrusion and avoidance reactions were prolonged over time when the participants had more difficulty reconciling their situation with their prior conceptualizations of their world and of their lives. However, regardless of the required cognitive processing efforts required, all participants had an

initial need to compartmentalize their experience. This was different from avoidance reactions in that it was a conscious process of not going backward or forward in time so that they could focus on the present and “be there” for the patient. This reaction was present until the participants’ appraisal of the patient condition was such that they believed that the patient was going to survive his or her injuries. An inability to consider the future was documented in a study of family members’ experience of waiting following a neurological crisis (Plowfield, 1999). Plowfield found that family members did not mention the future unless it was in reference to a return to a “sense of normalcy”. The findings of the present study further clarified Plowfield’s findings by showing that focusing on the present helped to maintain the participants’ sense of uncertainty and the hope that the patient could survive his or her injuries. In fact, the need to have hope has been identified as one of the top ten needs of family members of critically injured patients (Davis-Martin, 1994; Freichels, 1991; Leske, 1986; Rukholm et al., 1991). The study findings are also consistent with the finding that during this time period, participants did not want information about the patient’s prognosis, particularly if this information focused on negative outcomes.

Cognitive processing theory (Horowitz, 1986; Janoff-Bulman, 1992) addressed the assimilation or accommodation of the person’s cognitive schema to account for the current traumatic event. The theory focuses on the effect of the event in re-shaping the person’s basic assumptions about the world and the self. However, these authors do not discuss how this occurs over time. The study findings suggest that working through trauma-related thoughts and emotions during the early post-trauma period focuses on different levels of their cognitive structure. Initially, participants focused on what their current situation meant in relation to their prior conceptualization of how they made sense of their world. Their stories conveyed reflections about benevolence, justice, fairness and control. Their reflections were at a fairly general level of abstraction. As the patient improved and the participants were convinced that the patient would survive, they began to reconcile their current situation in the context of their lives more specifically. They also began to work on their conceptualization of the self in the context of how they had managed the traumatic event. Over time, their emerging conceptualization of the

world and of their lives informed each other based on their ongoing evaluation of their situation.

A number of authors have suggested that attributions helped to clarify and re-frame what happened into a context that may be compatible with the person's assumptions and beliefs (Janoff-Bulman, 1992; Thompson & Janigian, 1988; Weiner, 1985). The findings of the study showed that participants engaged in causal questioning as a strategy to reconcile their current situation with prior conceptualizations of the world and of their lives. Moreover, when they found a fit with which they were comfortable, they ceased to ask attributional questions. As such, the use of attributional questions was construed as a vehicle for the participants' cognitive work. The type of attribution used appeared context dependent and may provide information about the values and beliefs undermined by the traumatic event. However, what seemed more important was whether or not participants continued to ask themselves these questions over time. Continued questioning suggested continued cognitive efforts. The study also found that other strategies were used by participants to reconcile their perception of the current situation to prior conceptualizations of the world and of their lives. They engaged in an iterative process of comparing their evolving perceptions of the situation and of what it meant in the context of their world and of their lives. They reflected on the fit and initially used a variety of story telling activities in working through trauma-related thoughts and emotions. Over time their story telling behaviour reduced and they began to shift their comparing and reflecting activities towards validating their newly found fit and evaluating it in the context of their lives.

The findings of this study can also be interpreted in the context of explanatory theory (Kleinman, 1988). Explanatory theory proposes that people explain their distress in a multitude of ways that reflect the diversity and complexity found within their belief systems. At the heart of these explanatory models, or maps as renamed by Williams and Healy (2001), is formulating answers to concerns such as 'Why me?' 'Why now' 'What is wrong?' 'How long will it last?' 'How serious is it?' 'Who can intervene or treat the condition?' It is suggested that the patients' rich view of the world and of their illness within that world gives rise to a better understanding of their illness, including its meaning to them and their expected recovery process (Bhui, & Bhugra, 2002). One study

of caregivers of persons with both physical and cognitive impairments (Ayres, 2000) found that people's ability to formulate explanations played a crucial role in their construction of meaning in the caregiving experience. Although these explanations resembled appraisals, they were found to be broader in scope and went beyond evaluations of events as threatening or benign. In fact, they served to integrate particular experiences with caregiver's more general meanings. Furthermore, their explanations were based on personal philosophies, moral principles, or strongly held impressions about the nature of the world, about themselves, about their families and friends, or about caring. As events unfolded, caregivers made sense of their situations and responded to them, and those responses both rose out of previous expectations and engendered new ones. One shortfall of this theoretical perspective is that the process involved in formulating explanations is not fully described. However, these theoretical premises in combination with the findings of the current study, suggest that explanatory models result from a process of appraising the current situation in the context of past experiences, values and beliefs. Furthermore, questioning or attribution-making is considered central to the process of formulating explanations, and resulting explanatory models lead to the construction of meanings.

Another finding of this study was that as participants worked at reconciling their situation with prior conceptualizations of their world and of their lives, they tended to maintain or re-establish a positive stance in relation to the impact of the event on their values and belief system about the world, the self, and life. This is consistent with the literature on positive illusions. Taylor (1983) proposed that illusions are helpful in bringing about psychological adaptation. The idea that normal mental functioning depends on illusions has gained more support (Beaumeister, Heatherton, & Tice, 1993; Miller, 1989; Murray, Holmes, & Griffin, 1996; Taylor & Brown, 1999). More recently, studies have shown that both the social world and cognitive-processing mechanisms impose filters on incoming information that distort it in a positive direction (Phipps, Di-Pasquale, Blitz, & Whyte, 1997; Taylor & Armor, 1996). These findings are consistent with the findings of this study. During the initial post-trauma period, participants did not want to hear negative information, particularly information about the patient's prognosis. As the patient improved, their appraisal and monitoring of the patient were focused on

signs of the patient's recovery. Moreover, participants began to reflect on how they had benefited from their experience with the traumatic event and most reported having been positively transformed by their experience. As suggested in the literature, participants worked at regaining or maintaining a positive outlook on their situation and how they conceptualized their world. As participants began to take into consideration that their lives might be altered forever, they began to consider the negative impact of the event on their everyday life and life goals. However, they continued to maintain a positive bias, although perhaps less positive than before the accident, at the level of their overall values and beliefs about their world and their lives generally. These findings are consistent with Janoff-Bullman's (1992) comment that positive illusions may be adaptive at the level of a person's core assumptions but need to be more accurate at the level of their lower-order postulates.

In keeping with the notion of positive illusions, the participants in this study tended to consider uncertainty in a favourable light. During the first phase, they did not want to hear information about prognosis in part because of their need to continue to believe that a positive outcome was possible. They focused on characteristics of the patient that would see him through this situation thereby enhancing their perception of a probable recovery. During phases II and III, participants continued to view uncertainty as a friend, despite a realization that life would probably never be the same again. As such, uncertainty helped them to maintain the belief that a good recovery was possible. These findings are similar to those in a recent study of uncertainty in family members of patients with a severe traumatic brain injury (Duff, 2002). In contrast, those participants in the current study who had poor prior relationships with the patient and others in their life considered uncertainty as more threatening. They expressed difficulties in "being with" and "working with" the patient and therefore did not have access to cues that would help them to determine the patient's post-trauma status. Moreover, they did not have the advantage of reframing support if they had difficult relationships with others. Mishel (1988) described uncertainty as the cognitive state created when a person cannot adequately structure a situation due to lack of sufficient cues. This is seen to hamper the formation of a cognitive structure. Mishel identified two key processes in the appraisal of uncertainty: inference and illusion. Inference evaluates uncertainty using related

examples one can recall and is built on personality dispositions such as learned resourcefulness, sense of mastery and locus of control. She advances that if inference is used to appraise uncertainty, then a danger appraisal occurs. In contrast, if illusions are used, then an opportunity appraisal follows. The notion of uncertainty as the result of a person's appraisal of cues about the situation is consistent with the findings of this study. However, in contrast to Mishel's definition of inference, past experiences were considered by most participants as beneficial in making them stronger to cope with the head injury of their loved one, provided they had come to term with these. Hilton (1994) extended Mishel's (1988) work by recognizing that uncertainty included appraisal over time that incorporated the assessment of the person's situation and coping responses using emotions, cognition and chosen value systems to help define their experiences. The findings of this study are consistent with Hilton's definition of uncertainty in that participants appraised their situation over time by obtaining cues about the patient, which they interpreted in light of their value and belief structure. She does not address the role of past experiences specifically but in light of the results of this study, the inclusion of values and beliefs better accounts for the role that past experiences play in informing appraisal of the current situation. Penrod (2001) and McCormick (2002) further refined the concept of uncertainty by pointing out that the person's perception of their situation is central to understanding this concept. In addition, perceptions of confidence and control are seen to balance the effects of uncertainty to achieve a relatively steady state of mind (Penrod, 2001). These findings are in keeping with those of this study where participants tended to assess themselves as stronger than most, and which in turn contributed to the perception of her situation. Penrod concluded by proposing that the investigation of uncertainty be extended to move from interpretive theory to disclosive and explanatory theory. These perspectives are consistent with the findings of this study, which outlines a process of constant comparisons where the person interprets their current situation in light of prior conceptualizations of the world and of themselves. The results of this process shape their interpretation of the situation, including their view of uncertainty, which in turn leads them to derive new meanings. These findings are also consistent with the literature on explanatory models (Kleinman, 1988).

As discussed earlier, support emerged as a mediator of the process of reconciling the participants' perceptions of their situation with prior conceptualizations of the world and of their lives. Close others were instrumental in helping the participants in working through trauma-related thoughts by validating their evolving perceptions of the situation and how it fit within their prior conceptualizations of the world and of their lives specifically. However, when the relationship had not been close, participants described confiding as risky, and they avoided expressing their trauma-related thoughts and emotions. In fact, when relationships had been difficult, attempts at validation and cognitive re-framing were often detrimental to the participants' cognitive work of healing. A number of studies have shown a significant relationship between positive, close and emotionally sustaining relationships and high levels of psychological adjustments during times of stress (Blazer, 1982; Miller & Lefcourt, 1983; Pierce et al., 1991; Pierce et al., 1997; Ullman, 1996; Umberson et al., 1996). Furthermore, the presence of a confiding relationship has been associated with lower levels of emotional distress post-trauma and more likelihood of finding meaning in the event (Harvey et al., 1991; Pennebaker & O'Heeron, 1984; Pennebaker et al., 1988; Pennebaker & Susman, 1988; Pennebaker et al., 1989; Petrie et al., 1995; Silver et al., 1983; Sorenson et al., 1993). In fact, there are indications in the literature that social relationships may be particularly important to women's health (Hurdle, 2001). However, Charles Figley's work (1989, 1995) with family members of traumatized patients has shown that family members are victimized by secondary intention and may not be able to tolerate each other's trauma-related thoughts and emotions. In contrast to Figley's findings, most participants in the study were able to share their perceptions of the experience with close others, and they found a reciprocal benefit in doing so. However, when the pre-trauma relationships had not been close they had difficulty journeying together and as a result, they were upset by other's reactions to the traumatic situation. These findings are in keeping with those of a study of family members of patients with breast cancer that found sharing meaning to be a central strategy for families (Hilton, 1994). Hilton found that the more similarly the couples viewed the importance of verbal communication, the more satisfied they were with the relationship, the more supported they felt, and the better their adjustment to the diagnosis and the treatment. However, regardless of the

communication pattern, almost all of the couples in that study felt that it helped to talk with others. In addition, they reported experiencing a decrease in their desire to talk about the cancer and related issues and fears over time. Similarly, the participants in this study also reported that their need to speak about their relative's accident decreased over time. Together, these findings are in keeping with the literature on story-telling (Harvey, 1991; Orbuch et al., 1994) which suggest that talking helps the person process the traumatic event and that as the person successfully assimilate or accommodates the event in their cognitive schema, the need to talk about the event decreases. Together, these findings suggest that the benefits of support need to be examined in the context of the quality of the person's social pre and post trauma relationships.

Professional support also emerged as a potential mediator of the participants' cognitive processing. In the grounded theory, it was distinguished from the concept of social support, as it appeared to have different dimensions. The study findings showed that the participants did not have the same expectations of support from health care professionals as they had from close others. Moreover, participants did not perceive a commitment from health care professionals to supporting the whole family during the early phase of recovery. The relationships tended to be unidirectional and limited over time. Although there is a historical belief that nursing support constitutes an essential component of practice, there is a lack of clarity about what constitutes nursing support with family members. A number of studies have examined nurses' supportive behaviours (Day & Stannard, 1999; Fosbinder, 1994; Hupcey, 1998; Robinson, 1996). Robinson (1996) suggests that family members emphasize relationships with nurses over what professionals would call interventions. She also found that over time, families moved from a complete and unreserved trust in health care professionals to disillusionment, and then to a reestablishment of limited trust in particular health care professionals who proved trustworthy. Establishing trust involved the nurse's relational stance of curious listener, compassionate stranger, non-judgemental collaborator, and mirror for family strengths. Although some supportive nursing behaviours have been identified in the literature, there is a lack of both a meaningful and clear explanatory model and organizing framework for nursing support interventions with family members. The findings of the current study suggest that health care professionals may provide important

emotional, instrumental, informational and appraisal support in the context of the person's cognitive work of healing, particularly when the person's pre-trauma supports had been poor. The potential of professional support to be significant in the process of finding meaning is surely important as most participants found the process of participating in the study helpful in working through their traumatic experience. A number of contextual conditions, including re-structuring of nursing delivery systems may have contributed to the limited support from health care professionals perceived by the participants of this study. The role of professional supports in the process of finding meaning therefore requires further study.

Consequences of the Traumatic Event

Participants' psychological responses to the traumatic event in this study resulted in finding a new order and direction in their lives, and in a marked decrease in levels of emotional distress. As they reconciled perceptions of their current situation in the context of their prior conceptualization of the world and of their lives, participants described regaining a sense of focus and control over their lives. Most participants also began to express how the event had changed their priorities in life and given them a new sense of direction and purpose. The process of finding meaning was by no means complete by the time participants returned home but was ongoing as they worked at resuming life and adjusted to the patient's post-trauma deficits and behaviour. Although participants readjusted their expectations for the possibility that life would be altered forever, none of the participants gave up hope for a possible positive future. These findings are in keeping with the premise of the McGill Model of Nursing (Gottlieb & Rowat, 1987), which suggests that people can potentially rally from the negative effects of stressor events. The model further proposes that people cope with adversity by focusing on goal-oriented behaviours that provide a sense of purpose and meaning. In fact, all of the participants in the study have shown an extraordinary ability to learn and cope with what would otherwise seem like a senseless event in their lives. The findings are also in keeping with Thompson and Janigian's (1988) definition of meaning. They conceptualize meaning in terms of having a sense of order and purpose. More specifically, order pertains to the notion of stability and predictability that allow for

planning to occur, and purpose relates to having goals and goal-directed behaviours. The findings of the current study further clarify Thompson and Janigian's theory by differentiating the process of finding meaning from found meaning. The findings of this study can also be interpreted from the perspective of the concept of self-transcendence. Self-transcendence is defined as the ability to reach beyond constraints of the here and now so peace, contentment, and personal meaning can be found within a difficult life situation (Coward, 1996; Reed, 1991). Based on a study of caregivers of adults with dementia, Reed (1995) proposes that a person integrates perceptions of his or her past and future to enhance the present. More specifically, Levington and Gruba-McCallister (1993) maintain that one's experiences, both good and bad, can promote growth towards personal wholeness and integrity with a move from a place of self-centeredness toward a broader view of life. Furthermore, critical life events can serve as the impetus for change and growth because all individuals have an instinctive drive to move in a transcendent direction. These theoretical assertions support the findings that all of the participants in this study found some degree of personal meaning following their loved one's traumatic brain injury. Similarly, Man (2002) reported that caregivers became empowered after the onset of their family members' brain injury. These caregivers identified contributing factors such as setting clear personal expectations and adjustment of personal life goals, strong motivation, awareness of their own powerless state and willingness to ask for help from different sources. These factors were most evident during Phases II and III in the current study.

As participants began to reconcile trauma-related thoughts and emotions, they reported decreased levels of emotional distress as measured by the BSI® (Derogatis, 1977). Although as a group, participants did not exceed the cutoff for this scale. These findings are consistent with findings of a recent study which found that relatives of patients with even severe head injuries were not universally distressed (Perlesz, Kinsella, & Crowe (2002). However, a few of the participants in the current study experienced high levels of emotional distress as measured by the BSI® (Derogatis, 1977). This was particularly true for those who had difficulty assimilating the traumatic event and those who had poor pre-trauma relationships with close others and with the patient. However, their scores were below the cutoff for the scale at the time of the second interview

suggesting that they also began to successfully reconcile their experience. Together, the findings of this study support the concept of meaning as a healthy indicator of psychological adjustment as outlined by the McGill Model of Nursing (Gottlieb & Rowat, 1987).

Limitations of the Study

Several shortcomings of the present study need to be considered. They will be discussed in the context of the four aspects of trustworthiness outlined by Guba (1981) and Lincoln and Guba (1985). The first criterion relates to confidence in the truth of the findings for the participants and the context in which the study was undertaken. Although careful attention was given to limiting researcher interference during interviews, the researcher and research assistant were learning the art and the skill of interviewing. Initially they imposed too much structure on the interview process. However, when reviewing the taped interviews, they reflected on their interviewing techniques, which helped to improve their effectiveness in giving voice to the participants. Although resources did not allow for participants to review transcriptions of the taped interviews, a second interview allowed for validation of data and clarification of meanings. Although the three phases emerged distinctly over the two interviews, the third phase was observed at its onset. Therefore a third interview would have been beneficial in more fully describing this phase. The context of the study also posed challenges. The study took place at a time of change in the health care system and nursing delivery systems. Hospital mergers were ongoing in Ottawa, which affected workloads and the consistency of staffing on the units. In Vancouver, data collection occurred in the midst of job action and budgetary constraints. This also affected workloads and consistency of staffing on nursing unit. Moreover, these situations across sites could potentially have affected nurses' ability to "know" the patient and to provide family-centered care. As a result of these health care events, clinicians who recruited for the study were reassigned therefore necessitating frequent re-training of clinicians in the study protocol. The latter part of data collection also occurred in the context of the terrorist attack in New York on September 11, 2001. This overwhelming event had the potential to bias the participants' perception of their own traumatic experience.

Interviews were carefully examined for any references to this international event and none of the participants mentioned its occurrence. This is not to say that it had no effect on their experience.

The second criterion identified by Guba (1981) is applicability. Although the researcher interacted with recruiting clinicians regularly to enhance sampling of diverse and theoretically pertinent participant characteristics, access to participants was limited by the Ethics Committee requirements at each of the research sites. As a result, the researcher did not have access to potential participants until they had agreed to be approached and therefore needed to rely on clinicians to review admissions on a regular basis and to approach potential participants. As well, because it was a stressful time in the family members' life many may have felt too overwhelmed to participate. Although data was collected about rates of refusals, these reports may have been inaccurate in light of the flux in the system at each site. As a result, an important section of the population may have been omitted by refusing to participate or because clinicians did not think it appropriate to approach the mother or the wife. Also important to note is that the study recruited women only. This decision was based on evidence from the researcher's clinical practice and the literature suggesting that women tended to take on the role of primary caregivers following the head injury of a family member. The process of finding meaning after a head injury may be different for male caregivers.

The third criterion refers to consistency of the data (Guba, 1991). Unintentional variability in the data collection may have occurred because two sites were involved in the study. Although every effort was made to ensure consistency in selecting a quiet area for interviewing that was close to the patient, the units were busy places and interruptions were often impossible to control. Other sources of variability may have occurred because the researcher and research assistant conducted interviews at different sites. While regular debriefings and ongoing email communication limited sources of intentional variability, the differences in their approach and knowledge base as well as their own life circumstances may have contributed to breaks in the consistency of data collection.

The last criterion identified by Guba (1981) is neutrality. The use of constant comparative analysis is a strength of grounded theory methodology because it enhances applicability of the data. However, it is also a potential weakness because of the risk of

imposing a priori conceptualizations on the data. Even though a number of measures were taken to avoid researcher bias in interpreting the results, there is always the possibility that it informed the emerging model, especially when the researcher's area of practice is neuroscience nursing. Furthermore, although verification by the researcher's thesis supervisor using email and occasional phone conferences was ongoing, distance and their respective life context created limited opportunities for working together in verifying raw data, data reduction and analysis products, data reconstruction and synthesis.

Implications for Theory, Practice and Research

The results of this study about how mothers and wives find meaning during the early phase of recovery of their loved one's head injury has a number of implications for theory, practice and future research. These will be discussed in turn.

Implications for Theory

The concept of meaning has been of interest to nurses because of its focus on people's strength to overcome stressful life events and because it considers the person from a holistic perspective. These values and beliefs are reflected in the McGill Model of Nursing, which conceptualizes meaning as a healthy indicator of adjustment to stressors. The model focuses on people's ability to develop, learn and cope with adversity rather than on pathological indicators of adjustment. Although research about the concept of meaning is in its infancy, most of the studies to date have examined meaning in relation to psychological outcomes and the understanding of the process of finding meaning has remained largely unexplored in nursing studies. In contrast, a sizeable body of knowledge about how people make sense of traumatic events exists in the field of psychology. However, most of the focus has been on cognitive processing in the context of Post-Traumatic Stress Disorder thereby placing an emphasis on abnormal responses rather than normal responses. Research in that field is only beginning to describe the concept of meaning and to examine its contributions to successful processing of trauma events. As a result of the isolated efforts of these two disciplines, a number of theoretical assertions have emerged which have not been integrated into a model directly

applicable to clinical practice. The current study therefore makes two important contributions to theory.

First, the use of grounded theory has helped to outline a beginning description of the process of finding meaning. It is not sufficient to focus on meaning as a predictor, mediator, or indicator of psychological adjustment as has been the case in past research. Rather, being able to focus on the process helps to further define the concept and to learn how it operates in the context of the whole person. As such, it has greater potential to guide nursing practice. The grounded theory developed in this research uncovered a complex and dynamic process involving a number of clinically significant variables. It has also outlined the dynamics of the process over time. As such, the grounded theory developed in this study provides a starting place for furthering the development of a theory of meaning.

The second theoretical contribution of this study was to examine the grounded theory about the process of finding meaning after a head injury in light of the knowledge developed in the fields of nursing and psychology. While extreme care was taken to avoid imposing a priori theoretical views on the data during the constant comparative analysis process used throughout the study, the use of the emergent fit mode of grounded theory, as described by Artinian (1988), helped to consolidate, extend, and refine theoretical assertions that have emerged from the scholarly work in these two fields of study.

More specifically, the emerging grounded theory recognizes the importance of the person's perception of their situation as central to deriving meaning. These findings are consistent with the latest theoretical work on the concept of uncertainty (Hilton, 1994; McCormick, 2002; Penrod, 2001). However, the grounded theory adds to these theoretical assertions by outlining the context and factors that shape the person's perception, including their assessment of uncertainty.

The grounded theory further outlines how these perceptions are shaped through reconciliation with prior conceptualizations of the person's world and of themselves, and in light of his or her past experiences. As such, it extends the body of knowledge on cognitive processing which focuses more narrowly on how people attempt to assimilate or accommodate the traumatic event in their cognitive schema (Horowitz, 1986; Janoff-

Bulman, 1992). The process outlined in the grounded theory is also in keeping with explanatory theory (Kleinman, 1988), which focuses on how people's explanations about events shape their responses. In fact, the grounded theory adds to this body of knowledge by further outlining the process whereby a person arrives at an explanation. In addition, the grounded theory further situates people's explanations in the context of their social relationships with close others and professionals, and in the changing environmental context of the family-patient dyad.

Finally, the grounded theory further elaborates the concept of meaning as defined by Thompson and Janigian (1988) by describing a process whereby a person finds meaning in a traumatic event. Moreover, the grounded theory also supports the notion of self-transcendence as outlined by Coward (1996) and Reed (1995). In conclusion, the study has contributed towards the goal of integrating the current body of knowledge about the concept of meaning.

Implications for Practice

The deleterious effects of a head injury on family members have been well documented in the literature (Gervasio & Kreutzer, 1997; Hall et al., 1994; Livingston et al., 1985 a; 1985 b; McKinlay et al., 1981; Oddy et al., 1978). Clinical evidence also suggests that family members have a formidable capacity to rally and adjust to what would otherwise seem like a senseless event to most people. The findings of the study definitely corroborate these trends in the literature. At the same time, however, the literature has provided clinicians with little understanding of why some family members do well and others do not. As a result, they have felt powerless to intervene effectively with family members during the early phase of recovery. The focus of this study on the process of finding meaning, and the resulting grounded theory, therefore contributes to nursing practice in a number of ways.

First, the three phases identified during the early phase of recovery can help clinicians to understand the family members' reactions and needs in the context of the patient's condition and progress rather than in the context of the physical environment of the hospital units. While the physical environment had an impact on their reactions, the results of the study showed that the family members' unique perception of the patient's

status determined how she worked through trauma-related thoughts and emotions, and how she moved through the transitions between phases. As such, the patients and family members were connected on a journey that fluctuated based on the patient's condition. These results speak to the importance for nurses to practice from a phenomenological perspective.

Secondly, the findings of the study have undoubtedly shown that when a head injury occurs, the whole family is affected. This is consistent with the paradigmatic values and beliefs of the discipline, and if nursing practice is congruent with these values and beliefs, nurses must attend to the needs of the client and his or her whole family. The nurse must therefore journey with the family, and assessments, planning and interventions must be carefully guided by the family's perceptions and realities rather than by the clinicians' own perception of the patient's condition.

Thirdly, although disciplinary values and beliefs in family-centered nursing care have been reflected in nursing models, in nursing curricula, and in standards of practice, the study found that they have not been systematically implemented in practice. The findings revealed a number of contextual factors that may be responsible for this gap and need to be addressed by the current practice environment. Participants spoke to the lack of continuity in caregivers and the resulting difficulty in accessing pertinent information about the patient and treatment plans and goals and in establishing a therapeutic rapport. They also commented feeling frustrated by the mixed messages they received from a variety of health care professionals about the patient's condition and care. They were left with the feeling that the system's needs were addressed at the expense of the patients' and felt that health care professionals had no time for the family's needs. These findings may have been influenced in part by the re-structuring and job action that occurred at the research sites during the course of the study. However, participants mentioned system structures such as high workloads, casualization of the nursing workforce, the nursing shortage, and 12-hour shifts, as contributing to the lack of consistency in caregivers and the "patchwork" effect in the flow of information. Participants felt that health care professionals did not get to "know" the patient and family because the patient rarely had the same nurse care for him or her. They also felt that professionals adopted a business-

like stance to protect themselves from their patient's suffering. This may also be related to the increased workload demands and the increased patient acuity of practice settings.

A fourth implication for practice was the finding about the type of information required by family members over the three phases of recovery. Consistent with their need to compartmentalize their experience as they "wait to see" if their loved one will live, family members did not want information about the patient's prognosis, especially if this information was negatively biased. They had a need to believe that the patient could potentially recover from his or her injuries. They favoured uncertainty about the patient's prognosis. Supporting this need is not about offering false hope to families but rather, it is about assessing and intervening in concert with the individual journey. Once the patient was showing signs of improvement and the family felt ready to begin to "move on", they required information that helped them to see the situation in the context of what it would mean for the patient and their lives. They wanted information about the patient's prognosis and treatment plans and goals. Ironically, when they were ready for this type of information it was not readily available because as the patient improved, the family had less access to physicians and were exposed to more nurse caregivers. As the family began to "resume life", their need for information shifted towards gaining an understanding of how to work with the patient in order to ensure maximal recovery, and how to adjust life to the changes in the patient's condition. However, at this time, the family had usually lost contact with health care professionals while they waited for access to rehabilitation services. This left the family on hold and resulted in a sense of powerlessness to work in the patient's best interest, and fear that he or she would cease to progress. Moreover, family members felt that they had not been adequately prepared for the patient's discharge. These findings are consistent with those of a recent study by Paterson, Kieloch, and Gmiterek (2001) which found family members to not recall being taught about what to expect or resources available to them following the discharge of their head injured relative. In that study, health care professionals and insurance adjusters stated that extensive discharge planning and multidisciplinary teaching conferences with patients and their families had been held prior to discharge. The authors conclude that nurses need to pay attention to the amount, consistency, timing, and relevance of the information provided to family members prior to discharge. The

importance of individualizing educational experiences based on a caregiver's specific needs and issues was also identified in a recent study by Smith and Testani-Dufour (2002). In addition, that study pointed out the importance of nurses' interpersonal skills with patients and families as an important process component of any teaching program. These findings are consistent with the results of the current study, which speak to the information needs of family members over time. Furthermore, the current study highlights the importance of nurses' advocacy role in ensuring follow-up and access to appropriate health care providers and needed information in the context of a changing health care context. There may therefore be a need to re-consider primary nursing models for this population in the acute care setting and to pay careful attention to the restructuring of practice milieus such that nurses can practice to their full scope of practice. In the context of rapid and turbulent changes in the health care setting there is, more than ever before, a need for strong nursing leadership and for nursing practice to be guided by a strong philosophy of care.

Another implication for practice has to do with the need of family to "be with" and "work with" their head-injured family member during the early phase of recovery. Despite a sizeable relaxation of visiting policies in acute care units and hospitals generally, participants in this study continued to report that their access to the patient was often limited. Most blamed this on the nurses' concern for the patient's intracranial pressure. Study findings about the effects of family presence at the bedside on the patient's intracranial pressure have been mixed (Johnson, Omery, & Nikas, 1989; LaPuma, Schiedermayer, Galyas, & Seigler, 1990; Moseley, & Jones, 1001; Prins, 1989; Sisson, 1990; Snyder, 1983; Treloar, Nalli, Guin, & Gary, 1983; Walker, Eakes, & Siebelink, 1998). One possible explanation for these results may be that some patients may be more responsive than others to environmental input (Shaver, 1989). Given these findings, it is imperative that nurses carefully assess each family situation and the relative effects of visits by individual family members and tailor family visiting interventions based on each individual circumstance. In situations where the patient's intracranial pressure is labile, nurses can work in partnership with family members to decrease stimuli by making creative adjustments to visiting modalities (e.g. two-way windows, TV monitoring, frequent updates, short visits with limited verbal and physical contact) such

that the family could gain informational cues about their loved one's condition and progress. Other participants attributed inconsistencies in visiting policies to nurses attending to their needs rather than the family's or the patient's. Nurses must pay attention to balancing family and patient needs with system needs and to work in partnership with families in determining win-win strategies.

A sixth implication for practice based on the study findings has to do with the focus of nursing assessments. Past traumatic experiences, and particularly if these had not been successfully resolved, were found to shape the person's conceptualizations of their world and of their life, and to therefore affect the person's ability to reconcile the event. As well, although close others could be instrumental in helping family members to work through trauma-related thoughts and emotions by validating and providing re-framing support, they could also have a detrimental effect on their ability to work through trauma-related thoughts and emotions. In light of these findings, these are important foci for assessments as recognition of these factors can help identify families who are at high risk for negative outcomes. The assessment findings can also help guide planning and interventions. Nurses also need to assess how family members reconcile their current situations with prior conceptualizations of their world and of their lives. Because informational cues obtained from their unique "knowing" of the patient are so important to shaping their perception of the situation, it is important that they have access to appropriate data, and that nurses acknowledge that family members are expert on the patient. In fact, nurses should incorporate this information into their own assessment of the patient's condition. This is not to say that nurses do not do this. However, participants did not perceive that health care professionals considered their perspectives seriously. Perhaps this points to the need for nurses to take the time to acknowledge the family's perspective and to give voice to their observations as an integral part of their own professional assessments.

Finally, the results of this study suggest a need to pay attention to the role of professional support in the process of finding meaning. Professional supports have tended to be encompassed within the concept of social support. However the results of this study suggest that professional support may have different dimensions and properties and as such needs to be considered separately from the participants' social support.

Participants in this study have generally felt unsupported by health care providers and some have even felt “abandoned by the system”. Clearly, something is not happening in practice, which may have its roots in the contextual factors affecting practice at this time. However, one thing is clear and that is that health care professionals, and nurses in particular, have the potential to seriously influence the whole family’s cognitive work of healing. Through purposeful assessments and nursing interventions, nurses can shape how people review their values and beliefs about their world and their life in the context of their current situation. As such, they can enhance the person’s ability to find a new sense of order and direction in their life, which in turn has the potential to assist them in adjusting successfully to a traumatic event such as the head injury of a family member.

Implications for Further Research

The study results have implication for research and suggest several areas for further exploration. The focus of this study on the process of finding meaning following negative life events has shown that the examination of healthy indicators of adjustment contribute a unique and necessary perspective to knowledge development. Moreover, the use of grounded theory methodology with its focus on basic social processes has further contributed to a beginning understanding of the process of finding meaning after a traumatic event and to its applications to practice.

Although it is impossible to replicate the original conditions under which data was collected, or to control all the variables that might possibly affect findings, there is a need to reproduce this study with the goal of reaffirming the variables in the model and their relationships before testing of the theoretical relationships can be done. There is also a need to reproduce the study such that further variability can be introduced and test or extend our understanding of the process. For example, all of the patients in this study experienced some degree of recovery from their head injury. There is a need for future studies to include family members of patients whose condition did not improve or deteriorated to see if and how the process of finding meaning differed. As well, given that the study only recruited women caregivers, there is a need to test the theory by including male caregivers. There is evidence that having a sense of coherence has a buffering effect for women whereas its effect is less certain for men (Edwards & Holden,

2001). Another consideration in furthering our understanding of the process of finding meaning is that the current study interviewed the participants at two points in time and as a result, they were just beginning to enter the third identified post-trauma phase. A longitudinal study over the first year, including the acute care phase of recovery would further extend our knowledge of the process of finding meaning. There is also a need to study this process in other traumatic situations in order to determine if the theory has explanatory power. If the grounded theory is abstract enough and includes sufficient variation, it will apply to a variety of contexts related to the phenomenon under study and provide guidance with regard to intervention (Strauss & Corbin, 1990).

Another consideration for future trauma study relates to the importance of considering the nature of the traumatic event, the family's perception of the patient's condition, the occurrence of past traumatic events and whether they had been resolved, and the quality of the participants' past relationships with close others and with the patient. The study findings suggest that these variables can significantly influence the participants' ability to work through trauma-related thoughts and emotions. Although the unique context of the participants' situation such as income, occupation, education, and role in the family did not seem to influence the process of finding meaning in this study, the significance of these variables in other trauma studies suggest that these merit continued attention. It may be that their effect occurs later on the recovery trajectory.

Future studies also need to consider the characteristics and process of professional support. The findings of this study suggest that professionals have a potentially important role to play in fostering the family's adjustment to the head-injured patient's injuries and to the health care setting. Further exploration of the concept of professional support could provide a framework that can guide interventions and nursing practice. Moreover, given that professional relationships and family-centered care appeared to be important to the quality of the participants' experience, there is a need to further understand barriers and facilitators in the current context of the health care system with the goal of informing restructuring and policy decisions.

Another finding of this study that merits attention is the participants' concern for the interruption in the continuity of care and the lack of access to rehabilitation services as a result of recent cutbacks in health care. Family members described having felt

abandoned at the time of discharge and expressed fears that it would negatively impact the patient's chances towards a better recovery. Models such as primary care and managed care may provide for a better coordination of care and follow-up after discharge for this population of patients. The current interruption in health care services after discharge from the acute care setting requires further examination for its relationship to family and patient outcomes.

Finally, the researcher gained increased appreciation for the complexity of undertaking a clinical study. One of the most important realizations was the critical role that clinicians play in the recruitment of potential study participants. Dedicated and committed clinicians were truly the cornerstones in facilitating access to the data necessary for the development of this grounded theory. Moreover, the researcher also learned that ongoing communication and support between clinicians, researcher, and research assistants was paramount in exploring a process that occurred over a long period of time with vulnerable clients.

Conclusion

Since the 1970s, studies involving family members of the head-injured have tended to highlight pathological responses to the traumatic event and to the patient's injuries. Clinical evidence suggests that many family members are able to rally in the face of adversity and find meaning in a situation that could otherwise seem like a senseless event in their lives. Although the concept of meaning has gained popularity in the trauma research literature over the last decade, there has been a lack of attention given to the process of how a person maintains or restores a sense of meaning following traumatic events. Moreover, there has been a lack of synthesis of emerging theoretical assertions, especially across disciplinary boundaries.

The present study augments our understanding of people's psychological responses to traumatic events through the development of a grounded theory outlining the basic social process of how a person makes sense of their current situation in the context of their prior conceptualizations of the world and of their life. The results showed this process to begin during the immediate post-trauma

period and to evolve over time in concert with the patient's healing trajectory. Three phases were outlined during the acute care phase of recovery that may be helpful in assessing and planning the care of family members of the head-injured. Furthermore, a number of causal, intervening, and contextual conditions were identified which may assist nurses in the early identification of families who may be at risk during the early phase of the patient's recovery. Together, these findings contribute to the refinement and extension of current theoretical relationships emerging from the fields of nursing and psychology.

The study results showed that when a head injury occurs, the whole family is affected and therefore needs to be considered as the unit of care. The study results outlined the family's perceived reality in the context of their loved one's injury and of their experience within the health care system. The results have shown that family members perceived little professional support in dealing with the traumatic situation in their lives and in navigating the health care system. In the recent context of system cutbacks, the role of nurses as client advocates and facilitators of the health and healing process of families is more important than ever before. The health care system in Canada is ripe for reform and nurses must embrace the responsibility of their full scope of practice, and take the lead in creating acute-care environments that are conducive to the health and healing processes of the whole family. Given the current emphasis on early discharge, nurses have a moral imperative to ensure that families are prepared and supported in their work of healing so that they can begin to "resume life".

Overall, this study joins a growing body of research and knowledge in Nursing that focuses on healthy processes of adjustment following adverse life events. The understanding gained about the cognitive process involved in the search for meaning after the head injury of a loved one will provide more direction to the conduct of clinical assessment activities and will further inform the development of evidence-based interventions that could facilitate the healing of families in the early phase of the patient's recovery.

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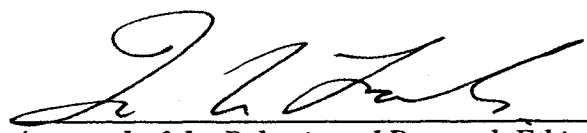
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APPENDIX A - Ethics¹

¹ Note: The regulations at the University of British Columbia and the Vancouver Hospital require that the Principal Investigator (PI) be an independent researcher with an appointment at the University of British Columbia. Therefore, Dr. Carol Jillings agreed to serve as PI for the purposes of data collection for this study at the Vancouver Hospital.



Certificate of Approval

PRINCIPAL INVESTIGATOR Jillings, C.J.R.	DEPARTMENT Nursing	NUMBER B0-0168	
INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT Vancouver Hospital & HS Centre ,			
CO-INVESTIGATORS: Van Neste-Kenny, Jocelyne, Nursing			
SPONSORING AGENCIES			
TITLE: Attributions, Social Relationships and Psychological Adjustment of Mothers and Wives of the Head Injured During the Acute-Care Phase of Recovery			
APPROVAL DATE MAY 26 2000	TERM (YEARS) 1	AMENDMENT:	AMENDMENT APPROVED:
CERTIFICATION: <p>The protocol describing the above-named project has been reviewed by the Committee and the experimental procedures were found to be acceptable on ethical grounds for research involving human subjects.</p>  <p><i>Approval of the Behavioural Research Ethics Board by one of:</i> Dr. I. Franks, Associate Chair Dr. R. Johnston, Associate Chair Dr. R. D. Spratley, Director, Research Services</p> <p>This Certificate of Approval is valid for the above term provided there is no change in the experimental procedures</p>			



June 23, 2000

Investigator: Dr. Carol Jillings, RN, PhD
Patient Services
C/o Jocelyn Van Neste-Kenny
2083 Valley View Drive
Courtenay, B.C. V9N 8L9

Vancouver Hospital Research Project # V00-0086

FINAL CERTIFICATE OF APPROVAL

TITLE: *Attributions, social relationships, and psychological adjustment of mothers and wives of the head injured during the acute-care phase of recovery.*

This is to inform you that your project has been approved and can start immediately. Approval has been granted until May 26, 2001 based on the following:

1. The University of British Columbia Ethics Committee approval.
2. VHHSC Research Affairs approval.


Yours truly,



Dr. Bernie Bressler
Vice President, Research



Certificate of Approval

PRINCIPAL INVESTIGATOR Jillings, C.J.R.	DEPARTMENT Nursing	NUMBER B00-0168	
INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT Vancouver Hospital & HS Centre ,			
CO-INVESTIGATORS: Van Neste-Kenny, Jocelyne, Nursing			
SPONSORING AGENCIES			
TITLE: Attributions, Social Relationships and Psychological Adjustment of Mothers and Wives of the Head Injured During the Acute-Care Phase of Recovery			
APPROVAL DATE MAR - 6 2001	TERM (YEARS) 1	AMENDMENT:	AMENDMENT APPROVED:
CERTIFICATION: <p>The protocol describing the above-named project has been reviewed by the Committee and the experimental procedures were found to be acceptable on ethical grounds for research involving human subjects.</p> <div style="text-align: center;"> <hr/><i>Approval of the Behavioural Research Ethics Board by:</i> Dr. R. D. Spratley, Director, Research Services</div> <p>This Certificate of Approval is valid for the above term provided there is no change in the experimental procedures</p>			

Letter of Information – Vancouver Hospital

Title of the project: The process of finding meaning after a head injury: The experience of mothers and wives during the early phase of recovery.

Thank you for considering speaking to me about participating in this study. I am a nurse and a doctoral candidate at McGill University in Montreal. I am conducting a nursing study with wives and mothers of patients who have suffered a head injury. The purpose of the study is to understand how mothers and wives of the head-injured adjust during the first 6 weeks following the injury. It is thought that adjustment during the early period following the injury may be important for long-term adjustment of the whole family. I hope that findings from this research will help improve the nursing care of head-injured patients and their family in the future.

Your participation in the study would involve answering some background questions, and filling out 4 questionnaires followed by an interview on two occasions. A meeting time and place would be arranged 2 weeks and 6 weeks after your family member's injury. Answering the questionnaires and interview would take approximately 60 minutes each time. The information that you share would be kept confidential. Your participation in this study would be voluntary and you would have the right to withdraw at any time. Your participation or withdrawal would in no way affect the care of your family member and your relationship with the health care professionals involved in his care.

Should you agree to talk further to me about participating in the study, I ask that you provide the nurse giving you this letter with a telephone number where I can contact you. If you are unsure whether or not you would like to speak to me, I encourage you to think about it over the next few days and either get back to the nurse or myself at any of the telephone numbers below. I am aware that this is a very stressful time for you and your family. I assure you that every effort will be made to be flexible and understanding.

Thank you for your consideration of this research study.

Sincerely,

Jocelyne Van Neste-Kenny, R.N., MScN
Home: toll free at 1-877-677-2030

Vancouver Hospital : Patient Service Coordinator
Telephone # _____

participant #: _____

Consent Form – Vancouver Hospital

Title of the Research Study: The process of finding meaning after a head injury: The experience of mothers and wives during the early phase of recovery.

Principal Investigator: Dr Carol Jillings, R.N. PhD
Associate Professor, UBC School of Nursing

Co-Investigator: Jocelyne Van Neste-Kenny RN, MScN
PhD (candidate), McGill School of Nursing, Montreal
This research is in partial fulfillment for the degree of PhD

Purpose

The purpose of this study is to understand how mothers and wives of the head-injured adjust during the first 6 weeks following the injury. It is thought that adjustment during the early period following the injury may be important for long-term adjustment of the whole family. The information provided may help nurses to improve the nursing care of head-injured patients and their family in the future.

Procedure

Your participation in the study will involve answering 4 questionnaires on 2 occasions (2 weeks and 6 weeks after your family member's injury). This will take approximately 60 minutes each time. Each session will be audiotaped in order to ensure that no information is lost. As well, information about the type and extent of your family member's injuries as well as his date of admission and discharge from the hospital will be obtained from the nurse.

Risks and benefits

Although you will not directly benefit from participating in the study, the information gained may be useful in assisting the mothers and/or wives who go through a similar experience. There are no foreseeable risks or harm involved by participating in the study. However, should you feel some emotional discomfort during the completion of the questionnaires, a referral to a health care professional on the trauma team will be offered.

Confidentiality

The data from the study will be coded so it will not be linked to your name. Your identity (or your family member's) will not be revealed. Your consent form and identifying code will be kept in a locked filing cabinet and destroyed by a shredding process after the completion of the study. The audiotape will also be identified with your code number and the tape will be destroyed following transcription. The Research Ethics Committee at the Ottawa Hospital and the principal investigator's dissertation committee at McGill University will have access to the coded and transcribed information. Only general results of the study will be published.

Participation

Your participation in the study is voluntary. You will be free to withdraw your consent and to discontinue your participation in the project at any time or refuse to answer any questions without prejudice to the medical care in which you and your family member are entitled to receive. Any

questions that you have about the project will be answered if not immediately, then at the end of the study.

Informed consent

The purpose and procedures of the above research project have been explained to me and all my questions about it have been answered to my satisfaction. I have received a copy of this consent form. On the basis of the above statements I agree to participate in this study.

Name of the participant (please print)

Relationship to the patient (please print)

Date

Signature of the participant

Date

Principal investigator / research assistant
(please print)

Signature

Date

Witness (please print)

Signature

Contact numbers

- A. For questions regarding the study, please feel free to contact the Principal Investigator

Dr Carol Jillings, RN, PhD
Office: (604) 822-7479

or co-investigator:

Jocelyne Van Neste-Kenny RN MScN, PhD (candidate)
Telephone number: toll free at 1-877-677-2030

For questions relating to your rights as a study participant please contact
Dr Richard Spratley
Director of the UBC Office of Research Services and Administration
Office: (604) 822-8598

Research summary

I would like a summary of the study findings upon completion of the study:

Yes: _____

No: _____

Mail to:



The Ottawa
Hospital

L'Hôpital
d'Ottawa

Research Ethics Board
Conseil d'éthique en recherches
761-4146 ~ 761-4902 ~ 761-5072
Fax No. ~ 761-4920

Thursday, November 04, 1999

Ms. Jocelyne Van Neste-Kenny
2083 Valley View Drive
Courtenay, British Columbia
V9N 8L9

Dear Ms. Van Neste-Kenny:

Re: Protocol # - 1999132-01H Attributions, Social Relationships, and Psychological Adjustment of Mothers & Wives of the Head Injured During the Acute Care Phase of Recovery

Protocol approval valid until - Friday, November 03, 2000

Thank you for your letter dated October 22, 1999. You have met the requirements of the Board and the above listed project has been granted approval by the Research Ethics Board. Approval is for the protocol dated May 17, 1999, the revised English Letter of Information, Consent form, Letter of Information - Civic Site, and Consent Form - Civic Site, and the French Letter of Information and Consent form. No addenda may be made in the protocol or the consent form without the Research Ethics Board review and approval.

The validation date should be indicated on the bottom of all consent forms and information sheets (see copy attached). Approximately one month prior to that time, a single renewal form should be sent to Research Services.

Medical Research Council guidelines require a greater involvement of the Research Ethics Board in studies over the course of their execution. You must maintain as part of your records copies of the signed consent form. As well, you must inform the Board of adverse events encountered during the study, here or elsewhere, or of significant new information which becomes available after the Board review, either of which may impinge on the ethics of continuing the study. The REB will review the new information to determine if the protocol should be modified, discontinued, or should continue as originally approved.

Yours sincerely,

Raphael Saginur, M.D.
Chairman
Ottawa Hospital Research Ethics Board

Encl.



The Ottawa
Hospital

L'Hôpital
d'Ottawa

Research Ethics Board
Conseil d'éthique en recherches
761-4146 ~ 761-4902 ~ 761-5072
Fax No. ~ 761-4311

Friday, October 13, 2000

Ms. Jocelyne Van Neste-Kenny
2083 Valley View Drive
Courtenay, BC
V9N 8L9

Dear Ms. Van Neste-Kenny:

RE: Protocol# - 1999132-01H Attributions, Social Relationships, and Psychological Adjustment of Mothers & Wives of the Head Injured During the Acute Care Phase of Recovery
Renewal Expiry Date - Saturday, November 03, 2001

I am pleased to inform you that your Annual Renewal Request (listed above) was reviewed by the Ottawa Hospital Research Ethics Board (OHREB) and is approved. No changes, amendments or addenda may be made in the protocol or the consent form without the OHREB's review and approval.

Renewal is valid for a period of one year. The validation date should appear date should be indicated on the bottom of all consent forms and information sheet/letter (see attached copy). Approximately one month prior to that time, a single renewal form should be sent to the OHREB office.

The Tri-Council Policy Statement requires a greater involvement of the OHREB in studies over the course of their execution. You must maintain, as part of your records, copies of the signed consent form. As well, you must inform the Board of adverse events encountered during the study, here or elsewhere, or of significant new information which becomes available after the Board review, either of which may impinge on the ethics of continuing the study. The OHREB will review the new information to determine if the protocol should be modified, discontinued, or should continue as originally approved.

Yours sincerely,

Raphael Saginur, M.D.
Chairman
Ottawa Hospital Research Ethics Board

Encl.

Letter of Information – Ottawa Hospital

Title of the project: The process of finding meaning after a head injury: The experience of mothers and wives during the early phase of recovery.

Thank you for considering speaking to me about participating in this study. I am a nurse and a doctoral candidate at McGill University in Montreal. I am conducting a nursing study with mothers and wives of patients who have suffered a head injury. The purpose of the study is to understand how mothers and wives of the head-injured adjust during the first 6 weeks following the injury. It is thought that adjustment during the early period following the injury may be important for long-term adjustment of the whole family. I hope that findings from this research will help improve the nursing care of head-injured patients and their family in the future.

Your participation in the study would involve answering some background questions, and filling out 4 questionnaires followed by an interview on two occasions. A meeting time and place would be arranged with a research assistant 2 weeks and 6 weeks after your family member's injury. Answering the questionnaires and interview would take approximately 60 minutes each time. The information that you share would be kept confidential. Your participation in this study would be voluntary and you would have the right to withdraw at any time. Your participation or withdrawal would in no way affect the care of your family member and your relationship with the health care professionals involved in his care.

Should you agree to talk further to my research assistant or me about participating in the study, I ask that you provide the nurse giving you this letter with a telephone number where I can contact you. If you are unsure whether or not you would like to speak to me, I encourage you to think about it over the next few days and either get back to the nurse or myself at any of the telephone numbers below. I am aware that this is a very stressful time for you and your family. I assure you that every effort will be made to be flexible and understanding.

Thank you for your consideration of this research study.

Sincerely,

Jocelyne Van Neste-Kenny, R.N., MScN, PhD (candidate)

Home: toll free at 1-877-677-2030

Ottawa Hospital: Trauma Nurse: _____
 Telephone #: _____

(Valid until November 3, 2001)

Participant #: _____

Consent Form – Ottawa Hospital: Civic Campus

Title of the Research Study: The process of finding meaning after a head injury: The experience of mothers and wives during the early phase of recovery.

Principal Investigator: Jocelyne Van Neste-Kenny RN, MScN, PhD (candidate)

Purpose

The purpose of this study is to understand how mothers and wives of the head-injured adjust during the first 6 weeks following the injury. It is thought that adjustment during the early period following the injury may be important for long-term adjustment of the whole family. The information provided may help nurses to improve the nursing care of head-injured patients and their family in the future.

Procedure

Your participation in the study will involve answering 4 questionnaires on 2 occasions (2 weeks and 6 weeks after your family member's injury). This will take approximately 60 minutes each time. Each session will be audiotaped in order to ensure that no information is lost. As well, information about the type and extent of your family member's injuries as well as his date of admission and discharge from the hospital will be obtained from the nurse.

Risks and benefits

Although you will not directly benefit from participating in the study, the information gained may be useful in assisting the mothers and/or wives who go through a similar experience. There are no foreseeable risks or harm involved by participating in the study. However, should you feel some emotional discomfort during the completion of the questionnaires, a referral to a health care professional on the trauma team will be offered.

Confidentiality

The data from the study will be coded so it will not be linked to your name. Your identity (or your family member's) will not be revealed. Your consent form and identifying code will be kept in a locked filing cabinet and destroyed by a shredding process after the completion of the study. The audiotape will also be identified with your code number and the tape will be destroyed following transcription. The Research Ethics Committee at the Ottawa Hospital and the principal investigator's dissertation committee at McGill University will have access to the coded and transcribed information. Only general results of the study will be published.

Participation

Your participation in the study is voluntary. You will be free to withdraw your consent and to discontinue your participation in the project at any time or refuse to answer any questions without prejudice to the medical care in which you and your family member are entitled to receive. Any questions that you have about the project will be answered if not immediately, then at the end of the study.

Informed consent

The purpose and procedures of the above research project have been explained to me and all my questions about it have been answered to my satisfaction. I have received a copy of this consent form. On the basis of the above statements I agree to participate in this study.

Name of the participant (please print)

Relationship to the patient (please print)

Date

Signature of the participant

Date

Principal investigator / research assistant
(please print)

Signature

Date

Witness (please print)

Signature

Contact numbers

- A. For questions regarding the study, please feel free to contact the Principal Investigator

Jocelyne Van Neste-Kenny RN MScN, PhD (candidate)
Telephone number:

- B. For questions relating to your rights as a study participant please contact Ottawa Hospital Research Ethics Board at (613) 761-4902.

Research summary

I would like a summary of the study findings upon completion of the study:

Yes: _____

No: _____

Mail to:

(Valid until November 3, 2001)

participant #: _____

Consent to participate in a study concerned with the adjustment of mothers and wives of head-injured patients.

Consent Form - Ottawa Hospital: General Campus

Principal Investigator: Jocelyne Van Neste-Kenny RN, MScN, PhD (cand.)

The purpose and procedures of the above research project have been explained to me and all my questions about it have been answered to my satisfaction. I understand that if I agree to participate, I will:

- a. Answer 4 questionnaires followed by an interview on 2 occasions. This will take approximately 60 minutes each time.
- b. Each session will be audiotaped.
- c. Allow Jocelyne Van Neste-Kenny to obtain information from the nurse related to my husband / child's (circle one) hospital chart so that she may obtain information about the type and extent of his injuries as well as his date of admission and discharge from the hospital.

I further understand that:

- All information will be completely confidential and that my identity (or my family member's) will not be revealed
- My participation is voluntary
- My decision whether or not to participate will have no effect on the health care or services that my family member and I receive at this institution or elsewhere
- I am free to withdraw my consent and to discontinue my participation in the project at any time
- Any questions that I have about the project will be answered if not immediately, then at the end of the study
- While I am encouraged to answer all questions on the questionnaires, I am not obliged to do so

Risks and benefits

I further understand that:

- While I may not directly benefit from participating in the study, the information gained will be useful in the future in assisting others who go through a similar experience
- While there are no foreseeable risks or harm involved by participating in the study I may feel some emotional discomfort during the completion of the questionnaires and that a referral to a health care professional on the trauma team will be offered to me should feel a need for it

On the basis of the above statements I agree to participate in this project.

Name of the participant (please print)

Relationship to the patient (please print)

Date

Signature of the participant

Date

Witness (please print)

Signature

Date

Principal investigator / research assistant
(please print)

Signature

Contact numbers

A. For questions regarding the study, please feel free to contact the principal investigator

Jocelyne Van Neste-Kenny, RN, MScN
Home : toll free at 1-877-677-2030

B. For questions relating to your rights as a study participant please contact

The Ottawa Hospital Research Ethics Board at (613) 761-4902

Research summary

I would like a summary of the study findings upon completion of the study:

Yes: _____

No: _____

Mail to:

(Valid until November 3, 2001)

Lettre d'Information – Hôpital d'Ottawa: Général Campus

Titre du projet: The process of finding meaning after a head injury: The experience of mothers and wives during the early phase of recovery.

Merci de bien vouloir considérer nous donner l'opportunité de vous parler de cette étude. Je suis une infirmière et une candidate au Doctorat en Sciences Infirmières à l'Université McGill. Mon étude s'intéresse à l'ajustement des épouses et des mères de patients ayant souffert un traumatisme crânien. Plus particulièrement, je vise l'ajustement pendant la phase critique, c'est à dire pendant les premières six semaines après l'accident. Il semblerait que l'ajustement pendant cette période est important pour l'ajustement à long terme de la famille. J'espère que les résultats de cette étude nous aideront à améliorer les soins aux patients atteints d'un traumatisme crânien et leur famille.

Votre participation à cette étude consisterait à remplir 4 questionnaires en deux occasions. Une rencontre serait planifié avec une assistante de recherche soit 2 semaines et 6 semaines après l'accident de votre époux/enfant. Chaque rencontre prendrait environ une heure de votre temps. L'information que vous partageriez serait confidentielle et anonyme. Votre participation à cette étude serait volontaire et vous seriez entièrement libre de cesser de participer à cette étude à n'importe quel moment. Votre décision de participer ou non à l'étude n'affecterait pas les soins/services que votre époux/fils et vous-même recevriez de l'hôpital.

Si vous acceptez de nous donner l'opportunité de vous parler de cette étude, nous vous demandons de bien vouloir donner votre numéro de téléphone à l'infirmière qui vous donne cette lettre. Si vous n'êtes pas certaine de vouloir nous parler, nous vous incitons à y penser pendant les prochains jours. Si vous désirez qu'on vous parle de l'étude, vous pouvez nous rejoindre à un des numéros de téléphone ci-bas.

Nous sommes très conscients que vous et votre famille vivez une période très difficile. Nous nous engageons donc à être flexible et compréhensif.

Merci pour votre considération de ce projet.
Sincèrement,

Jocelyne Van Neste-Kenny, R.N., MScN, PhD (candidate)
Domicile: Sans frais à 1-877-677-2030

Hôpital d'Ottawa: Infirmière en traumatologie: _____
 Numéro de téléphone: _____

(Valide jusqu'au 3 novembre 2001)

Participant #: _____

Consentement de participation dans une étude concernant l'ajustement des épouses et mères de patients atteints d'un traumatisme crânien.

Formulaire de Consentement - Hôpital d'Ottawa: Général Campus

Chercheur principal : Jocelyne Van Neste-Kenny, R.N., MScN, PhD (candidate)

Le projet de recherche m'a été expliqué. J'ai eu l'occasion de poser toutes les questions sur les conséquences de ma participation à cette étude et j'ai reçu des réponses satisfaisantes. Si j'accepte d'y participer je comprends que :

- a. Je répondrai à quatre questionnaires suivis d'une interview en deux occasions. Chaque rencontre prendra environ une heure de mon temps.
- b. Chaque session sera enregistrée sur bande magnétique.
- c. Je permettrai à Jocelyne Van Neste-Kenny d'obtenir, par l'intermédiaire de l'infirmière, de l'information au dossier médical de mon époux/enfant (encercler) sur sa condition médicale, la date de son admission et la date de son congé de l'hôpital.

De plus, il est entendu que :

- Tous les renseignements sont confidentiels et anonymes
- Ma participation est volontaire
- Ma décision de participer ou non n'affectera pas les soins / services que mon époux / enfant (encercler) et moi-même recevrons à l'hôpital ou ailleurs
- Je suis entièrement libre de cesser de participer à cette étude à n'importe quel moment sans avoir à donner d'explications
- L'on répondra à mes questions sur l'étude soit immédiatement ou à la fin de l'étude
- Même si l'on m'encourage à répondre à toutes les questions, ceci est sans obligation de ma part

Risques et bienfaits

De plus, je comprends que

- Même si je ne bénéficiais pas directement des résultats de cette recherche, ma participation à ce projet, par l'information précieuse qu'elle apportera, sera utile à améliorer les soins pour ceux qui vivent une situation semblable
- Bien qu'il n'y ait aucun risque prévu à ma participation à cette étude, je peux ressentir de la détresse émotionnelle lorsque je remplie les questionnaires. Une consultation auprès d'un professionnel sur l'équipe de soin me sera offerte si j'en ressens le besoin.

Sujet aux conditions mentionnées ci-dessus, je m'engage à participer à ce projet.

Nom du participant
(en lettres moulées)

Lien avec le patient (en lettre moulées)

Date

Signature du participant

Témoin (en lettres moulées)

Date

Signature

Chercheur principal / assistant(e) de recherche
(en lettres moulées)

Date

Signature

Numéros de téléphone de personnes ressource:

- A. Si vous avez des questions au sujet de l'étude, contactez le chercheur principal

Jocelyne Van Neste-Kenny, RN, MScN
Domicile: sans frais au 1-877-677-2030

- B. Si vous avez des questions au sujet de vos droits comme participant à cette étude, contactez

Le Conseil d'éthique en recherches de l'Hôpital d'Ottawa au (613) 761-4902

Résumé de recherché

J'aimerais recevoir un résumé des résultats lorsque l'étude est complétée

Oui _____

Non _____

Poster à l'adresse suivante:

(Valide jusqu'au 3 novembre 2001)

APPENDIX B - Tools

Demographic Information (Tear-off sheet)

Participant number: _____

Participant's name: _____

Address: _____

Telephone number:	home	1- ()	_____
	business	1- ()	_____
	other	1- ()	_____

Head-injured patient - chart information

Patient's name: _____

Hospital #: _____

Patient's age _____

Medical diagnosis: _____

Surgical procedures following admission (type & date): _____

Circumstances of accident: _____

Wife and/or mother's name _____
(RA add participant number(s)) _____

Date of admission

ER: _____

ICU: _____

Ward: _____

GCS: _____ Scan results: _____

**** If trached/intubated upon arrival to ER and CT scan is positive:**

Scan results: _____

GCS (pre trach/intubation) _____

GCS (post trach/extubation) _____

participant #: _____

Demographic Information (Interview # 1)

Date: _____

Location of interview: _____

How old are you? _____

1. What is your present marital status?

☐ Legally married and not separated

How many years? _____

☐ Separated but still legally married

How many years? _____

☐ Common law

How many years? _____

☐ Divorced

How many years? _____

☐ Widowed

How many years? _____

☐ Never married (single)

3. Before the accident, did you live with your injured family member?

☐ Yes☐ No

If no, whom did your injured family member live with? _____

4. Household composition

Household member	Age	Sex	Relationship to you	Dependent Yes or No
1				
2				
3				
4				
5				
6				
7				
8				
9				
10				

Do you have any dependents not living in your household?

☐ Yes

If yes, how many? _____

☐ No

4. What is the highest level of education that you have completed?

- ☐ No schooling
- ☐ Elementary school
- ☐ Some secondary (high school)
- ☐ High school diploma
- ☐ Some trade, technical or vocational school or business college
- ☐ Some community college, CEGEP
- ☐ Bachelor's degree
- ☐ First professional degree in medicine (M.D.), dentistry (D.D.S., D.M.D.) veterinary medicine (D.V.M.), law (Ll.B.), optometry (O.D.) or divinity (M.DIV.), or 1 year B.Ed. after a bachelor's degree
- ☐ Some graduate studies at the Master's level
- ☐ Master's degree (eg. M.A., M.Sc., M.Ed)
- ☐ Some graduate studies at the doctorate level
- ☐ Earned doctorate (e.g. Ph.D., D.Sc., D.Ed.)

Other (please specify) _____

Total number of years of study: _____

5. Before the accident, were you

- ☐ Employed full-time
- ☐ Employed part-time
- ☐ Unemployed
- ☐ On sick leave
- ☐ Maternity/paternity leave
- ☐ Leave of absence
- ☐ Retired
- ☐ Other (please specify) _____
- ☐ On leave
- ☐ Full-time student
- ☐ Part-time student
- ☐ Keeping house / caring for children

What kind of work did you do before the accident? _____

5. What is your best estimate of the total income (before deductions) of all household members from all sources during the past 12 months ?

- ☐ Less than \$10,000
- ☐ \$10,000 - \$19,999
- ☐ \$20,000 - \$29,999
- ☐ \$30,000 - \$39,999
- ☐ \$40,000 - \$49,999
- ☐ \$50,000 - \$74,999
- ☐ \$75,000 - \$99,999
- ☐ \$100,000 or more

6. What is your ethnic background? _____

7. Are you affiliated with any religious group?

Yes ☐ what group? _____ No ☐

8. Do you attend regularly? ☐ Fairly regularly ☐ Rarely ☐ Not at all
9. Have you personally ever been hospitalized / injured in an accident?
 Yes ☐ If so, what kind of accident? _____
 No ☐
10. Has someone you care about ever been hospitalized / injured in an accident?
 Yes ☐ If so, what kind of accident? _____
 No ☐
11. To what extent do you feel that your husband / child's life was threatened? Place an *X* along the line below which best reflect your perception.
- Not at all* _____ *Threatened*
threatened
12. To what extent do you feel uncertain about your husband / child's recovery? Place an *X* along the line below which best reflect your perception.
- Certain* _____ *Uncertain*
13. To what extent do you feel burdened by the care of your husband / child ? Place an *X* along the line below which best reflect your perception.
- Not at all* _____ *Burdened*
burdened
14. To what extent do you feel a sense of loss as a result of your husband / child's accident? Place an *X* along the line below which best reflect your perception.
- No loss* _____ *Loss*
16. Did someone you know die in the accident?
 Yes ☐ if so, who? _____ No ☐
17. Was another person you care about involved in the accident as well?
 Yes ☐ No ☐
18. If the accident was a motor vehicle accident, who was driving? _____
19. Since the accident, have you consulted a professional to help you deal with your emotions?
 Yes ☐ If so, who? _____ No ☐
 If you answered yes to this question, how many times did you talk to this person? _____
20. Since the accident, have you attended a support group meeting to help you deal with your emotions?
 Yes ☐ No ☐
 If you answered yes to this question, how many times did you attend? _____

participant #: _____

Demographic Information (Interview # 2)

Date: _____

Location of interview: _____

1. Since the accident, have you been

- | | |
|---|--|
| <input type="checkbox"/> Employed full-time | <input type="checkbox"/> On leave |
| <input type="checkbox"/> Employed part-time | <input type="checkbox"/> Full-time student |
| <input type="checkbox"/> Unemployed | <input type="checkbox"/> Part-time student |
| <input type="checkbox"/> On sick leave | <input type="checkbox"/> Keeping house / caring for children |
| <input type="checkbox"/> Maternity/paternity leave | |
| <input type="checkbox"/> Leave of absence | |
| <input type="checkbox"/> Retired | |
| <input type="checkbox"/> Other (please specify) _____ | |

What kind of work have you done since the accident? _____

2. Since the accident, have you been affiliated with any religious group?

Yes ☐ what group? _____
No ☐

Have you attended regularly? ☐ Fairly regularly
☐ Rarely
☐ Not at all

3. Since the accident, have you consulted a professional to help you deal with your emotions?

Yes ☐ If so, who? _____ No ☐

If you answered yes to this question, how many times did you talk to this person? _____

4. Since the accident, have you attended a support group meeting to help you deal with your emotions?

Yes ☐ No ☐

If you answered yes to this question, how many times did you attend? _____

5. Since the accident, have you been prescribed medications?

Yes ☐ If so, what medication(s) ? _____
No ☐

6. To what extent do you feel that our first meeting made you think more about the reasons for the your child's/husband's accident?

Not at all _____ *A lot*

7. To what extent do you feel that our first meeting made you want to talk more about your child's/husband's accident with people close to you?

Not at all _____ *A lot*



Leonard R. Derogatis, PhD

Last Name First MI

ID Number

Age Gender Test Date

DIRECTIONS:

1. Print your name, identification number, age, gender, and testing date in the area on the left side of this page.
2. Use a lead pencil only and make a dark mark when responding to the items on page 3.
3. If you want to change an answer, erase it carefully and then fill in your new choice.
4. Do not make any marks outside the circles.

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USE ONLY FOR HAND SCORING**



Product Number
05627

	NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY	HOW MUCH WERE YOU DISTRESSED BY:
1	0	1	2	3	4	Nervousness or shakiness inside
2	0	1	2	3	4	Faintness or dizziness
3	0	1	2	3	4	The idea that someone else can control your thoughts

participant #: _____

Impact of Event Scale

(Horowitz 1979)

INSTRUCTIONS:

Below is a list of comments made by people after stressful life events. Please check (4) each item as it relates to your husband / child's accident, indicating how frequently these comments were true for you during the **past seven (7) days**. If they did not occur during that time, please mark the "not at all" column.

QUESTIONS	NOT AT ALL	RARELY	SOMETIMES	OFTEN
1. I thought about it when I didn't mean to.				
2. I avoided letting myself get upset when I thought about it or was reminded of it.				
3. I tried to remove it from memory.				
4. I had trouble falling asleep or staying asleep, because of pictures or thoughts about it that came into my mind.				
5. I had waves of strong feelings about it.				
6. I had dreams about it.				
7. I stayed away from reminders of it.				
8. I felt as if it hadn't happened or it wasn't real.				
9. I tried not to talk about it.				
10. Pictures about it popped into my mind.				
11. Other things kept making me think about it.				
12. I was aware that I still had a lot of feelings about it, but I didn't deal with them.				
13. I tried not to think about it.				
14. Any reminder brought back feelings about it.				
15. My feelings about it were kind of numb.				

Source: Mardi J. Horowitz, M.D., Professor of Psychiatry, University of California, 401 Parnassus Avenue, San Francisco, CA 94143.

participant #: _____

Meaningfulness in Life Scale

(Thompson 1992)

INSTRUCTIONS:

Indicate, by circling the appropriate number, the extent to which you agree with the following statements *at this time*.

QUESTIONS	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE
1. I know what caused this accident.	4	3	2	1
2. I feel that my life is meaningful right now.	4	3	2	1
3. I can't make sense out of what happened.	4	3	2	1
4. It seems very unfair that this accident happened.	4	3	2	1
5. There is nothing that I did to deserve this.	4	3	2	1
6. Since the accident, my life seems empty and meaningless.	4	3	2	1
7. I have important goals that I am working towards.	4	3	2	1
8. This accident will stop me from reaching important goals in my life.	4	3	2	1
9. This accident has disrupted all my plans.	4	3	2	1
10. Some positive things have come out of this experience for me.	4	3	2	1
11. I'm in a better situation than other people in similar situations.	4	3	2	1
12. Some parts of this experience make me feel particularly lucky.	4	3	2	1
13. I'm usually able to put the negative parts of this experience out of my mind.	4	3	2	1

Source: Dr. Suzanne Thompson, Department of Psychology, Pomona College, 550 Harvard Avenue, Mason Hall, Claremont, CA 91711-6358.



April 27, 1999

Jocelyne Van Neste-Kenny, R.N., MScN

7

Dear Ms. Van Neste-Kenny:

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Sincerely,

Kim M. Bartels, Ph.D.
Product Support Psychologist



MARDI J. HOROWITZ, M.D.
Professor of Psychiatry
Director, Center on Stress and Personality
Langley Porter Psychiatric Institute

Jocelyne Van Neste-Kenny, R.N., MScN
School of Nursing
McGill University

May 19, 1999

Ms. Van Neste-Kenny

I received your inquiry regarding the Impact of Events Scale and I grant permission for you to use the IES, as well as to include it in your thesis.

There are 15 items that make up the Impact of Events Scale (or IES). Each question can be rated by the subject on a scale of 1-4 with 1=not at all, 2=rarely, 3=sometimes, and 4=often. In order for the data to be used, the number of ratings must be recorded as follows:

- 1 becomes 0
- 2 becomes 1
- 3 remains 3
- 4 becomes 5.

In the version enclosed, rarely is already designated as 1, sometimes as 3, and often as five. Using these scores your data can be compared to data from other populations. There are two subscales of the IES, the Intrusion and Avoidance subscales.

The Intrusion subscale is made by adding items 1, 4, 5, 6, 10, 11, 14.

The Avoidance subscale is made by adding items 2, 3, 7, 8, 9, 12, 13, 15.

The sum of the scale is the sum of the Intrusion and Avoidance subscales.

The cutoff points for the global (Intrusion plus Avoidance scores) IES are as follows:

Low = below 8.5; Medium = in between; High = 19 or more.

We would appreciate receiving the results of your use of the scale if you have or might plan to publish them in scientific literature.

The journal citation for the IES is Horowitz, M.J., Wilner, N., and Alvarez, W. The Impact of Event Scale: A measure of subjective stress. Psychosomatic Medicine 41 (3) 209-218, 1979. You can also cite my book Stress Response Syndromes, Northvale, New Jersey: Aronson, 1976 first edition, 1996 third edition.

I do not advocate use of the Impact of Events Scale revised (IES - r). I consider the IES a better instrument for the following reasons:

The addition of the hyper arousal items in the Impact of Events Scale Revised is the major change. These items are not as sensitive and specific to the PTSD diagnosis, or to stress response syndromes in general as are the intrusions and avoidance items that exist in the IES, and that are retained in the IES - r. I think the reason that those hyperarousal items were added by those who constructed the IES -r is that such symptoms were included in DSM 3. But subsequent work, DSM 4, do not emphasize these sensitive and specific items. It is not that they are not important, hyperarousal symptoms are important in many stress response syndromes, but they are relatively non-specific and often not present. Also, there is a larger body of comparative scores available for the IES.

The instructions for the IES are different from the IES - r, so people who use the IES - r are getting a different kind of rating, although the scores probably would highly correlate. The reason is that the people who revised the scale are emphasizing the distress rather than frequency of occurrence. Distress is often colored by a number of other motives and qualities, and frequency over the past week is a relatively more comparable bit of data.

Best wishes in your endeavor,

Mardi J. Horowitz, M.D.
Professor of Psychiatry
University of California, San Francisco
Per NE

Jocelyne

From: "Jocelyne Van Neste Kenny" <[redacted]>
To: "Nanette" <[redacted]>
ent: Monday, January 06, 2003 7:09 PM
Subject: Fw: Permission to use instrument

----- Original Message -----

From: Suzanne Thompson
To: Jocelyne Van Neste Kenny
Sent: Thursday, January 02, 2003 7:48 AM
Subject: RE: Permission to use instrument

You have my permission to use the Meaningfulness in Life Scale in your research and to append a copy to your thesis.
Suzanne Thompson

-----Original Message-----

From: Jocelyne Van Neste Kenny [mailto:[redacted]]
Sent: Sunday, December 29, 2002 10:37 AM
To: [redacted]
Subject: Permission to use instrument

Dr Thompson,

I am a PhD candidate at McGill University in Montreal Canada. I am in the final stages of my dissertation study entitled "Finding meaning after a head injury: The experience of patients' mothers and wives during the early phase of recovery". We communicated in the Spring of 1999 at which time I requested your permission to use the Meaningfulness in Life Scale (1992) in my PhD thesis study. At that time, you mailed me a copy of the scale with an attached post-it note saying "FYI, I hope that it is helpful". I wonder if you could send me official permission to use the scale in my dissertation study and to append a copy of the scale in the final copy of my thesis which will be microfilmed for library use.

Sincerely,

Jocelyne Van Neste-Kenny RN, MScN, PhD (candidate)