Family impact and influence following severe traumatic brain injury

By Diane Duff

Abstract

Negotiating is the core variable or central concern of families who have a close relative in a state of post-comatose unawareness or minimal responsiveness following a severe traumatic brain injury. Family members negotiate with each other, with members of the health care team, and with others such as insurance agents, case managers, and representatives of the justice system on behalf of the injured individual. Family members also negotiate the intricacies of the health care system. These are the findings of a 16-month grounded theory study conducted on two acute neurosurgical units in Toronto, with 25 family members from 11 families who had a close family member who suffered a severe traumatic brain injury and who was in a state of post-comatose unawareness or minimal responsiveness. An extensive review of the scholarly literature related to family research methodology and family research related to families following the brain injury of a family member is also provided in this paper.

Introduction

The experience and needs of families following the brain injury of a family member has attracted the interest of many disciplines. There have been many published reports of clinical, theoretical, and research work about the impact, needs, and the injury-related burden of caregivers and families following the brain injury of a family member. A review of the published literature leaves the reader with an overwhelming impression of family burden and distress. However, little attention has been paid to the problems families face as individuals, subgroups, or as a family unit. Family appraisal, family capacity or resilience, the process of family adaptation, and effective family interventions during the early illness trajectory have not been studied in depth.

A severe traumatic brain injury happens to both the injured individual and the family. Although spontaneous healing accounts for much of the early recovery from a severe traumatic brain injury, injured individuals continue the processes of recovery and rehabilitation in a lifelong process, if sufficient support and resources are in place. Family members are the foundation of the ongoing support and resources that are provided. Their role begins with the first phone call and increases over time. While the injury itself will heal, lasting physical and neurological effects will persist and have a concomitant impact on close family members. Family survival is dependent on developing family survival strategies. These include pacing, articulating needs and concerns, advocating for the injured individual and the family, seeking support, being open to change, and becoming a brain injury expert.

Families need expert guides as they begin to grasp the impact of an injury with the magnitude of a severe traumatic brain injury and as they learn to influence its outcomes. Nurses in the acute care setting are in the privileged position of being present with families when the initial shock and disbelief regarding the injury begins to recede and they begin to perceive that recovery from a severe TBI is a slow and unpredictable process. Nurses have numerous opportunities on a daily basis to explore with family members their experiences, understanding, suffering, and situational uncertainty.

In this paper, I have focused on reviewing the scholarly literature related to family research and data-based studies concerning families following the brain injury of a family member, as well as presenting findings concerning families from a prospective study using grounded theory methodology that was conducted on two acute care neurological units in Toronto. In that study, I interviewed and observed members as a family unit who had a close relative in a state of post-comatose unawareness or minimal responsiveness to determine family needs and concerns when a relative was in a state of post-comatose unawareness (PCU) or minimal responsiveness (MR) following a severe TBI. The specific phenomenon of interest is the period of post-comatose unawareness and/or minimal awareness and responsiveness that frequently follows coma. This segment in the uncertain trajectory of illness begins as coma “lightens” and continues until the individual either recovers sufficient abilities to follow commands or the individual shows little or no neurological improvement over the course of a year post-injury. A detailed discussion of altered states of consciousness, theories of recovery, and assessment following severe traumatic brain injury was published in a previous article in AXON (Duff, 2001).

Family research

In his critical review of family research studies, Fisher (1982) noted “several glaringly repetitive problems” (p. 314) in the conduct and interpretation of family research. He stated that the most serious of these were oversimplification and inconsistencies between the research question, theoretical underpinnings, conceptualization of the family, unit of analysis, and procedures for collecting and analysing family data. Gilliss and Davis (1992) added failure to clearly define and describe the clinical phenomenon and the lack of research regarding family interventions as common problems. The following discussion will address these concerns.
Family definition

There are many definitions of family. Hanson and Boyd (1996) observed that recent definitions of family have evolved beyond the traditional “two parents who [are] bound by marriage, with one or more offspring” (p. 42) to reflect the diverse family compositions of today. A definition that embodies parsimony within a comprehensive and inclusive conceptualization of family is: “A family is a group of individuals who are bound by strong emotional ties, a sense of belonging, and a passion for being involved in one another’s lives” (Wright, Watson, & Bell, 1996, p.45). This definition and conceptualization of family allows for the recognition of significant members who would not be included within legal and traditional definitions of family, as members related by blood and marriage. It is respectful of gender issues and diverse cultural traditions. It also reflects a belief in the fluidity and evolution of family structure, function, and membership. However, an even more succinct definition of family is provided by Wright and Leahey (2000) “the family is who they say they are” (p. 70). This definition was used in the study, as it is consistent with the notion of family as “a socially constructed entity” (Hartrick, 1999, p.12).

Unit of interest and analysis

One of the most problematic areas of family research relates to the unit of interest and the unit of analysis. Family research can be done at the level of the family unit, family characteristics, family-as-environment, family-related, or nursing interventions with family (Feetham, 1984, 1991; Feetham, Gilliss, Meister, & Bell, 1993). However, recent distinctions have primarily divided nursing research with families into the categories of family research or family-related research (Feetham, 1984; Moriarty, 1990). This is determined by whether the family unit or group is the focus of the study or whether it provides context for the study of an individual family member (Gilliss, 1991). There are no easy rules to determining whether family research should be conducted using certain key informants, an aggregate, or an approximation of the whole family. The decision is based on the nature of the research purpose and question (Lynn, 1995; Uphold & Strickland, 1989). It requires the researcher to be clear concerning “what is empirically based in the individual and what is based in the family” (Gilliss, p.20). Additionally, there are pragmatic issues related to cost and feasibility of recruiting and maintaining multiple family members, analysis of multiple participant data, and the willingness to share sensitive data if data are collected from more than one family member in a group interview format (Uphold & Strickland).

Feetham (1991) distinguished family unit research as those studies that require the involvement and perspectives of more than one family member such as studies of “family functioning, decision-making, boundary regulation, and solidarity” (Moriarty, 1990, p. 2). Family-related studies focus on individual family member issues such as stress or caregiver role. Frequently, specified family dyads, such as mother-child, wife-husband, and dependent elderly individual-family caregivers have also been studied. Other family aggregate groups may also be studied such as members of a household. Moriarty considered any research that has more than one participant to be family research.

Robinson (1995) observed by focusing on the person as a family member that the part of the person that is separate from the family, which she calls the individual, has not been included in distinctions concerning family research. She suggested it is possible to unify the whole person, as an individual and family member, and focus on the person and the family asynchronously by shifting the focus from one perspective to the other, while always retaining the other as background. She proposed a schema with multiple distinctions for units of focus and analysis.

In designing family and family-related research studies, the key is to examine the fit between the research question, the chosen conceptual unit of interest, and the ability of the participant to address the area of interest. Family participants can legitimately provide information on their own characteristics. They can also provide information on their perceptions of other family members and relational properties between family members. However, such personal constructions must be consistent with the underlying theoretical and methodological framework of the study. In the study, the family unit was the unit of analysis. However, family aggregates, dyads, and individuals may become the focus of all or part of the study as the process of data collection and analysis evolves using grounded theory. If this becomes the case, the family unit will remain contextually important.

Complexity of family processes

Many authors who have engaged in critical analysis and debate concerning family research have observed the tendency to try to simplify the complexity of family transactions and to control the influencing variables. Family researchers have generally failed to develop necessary methods and procedures capable of measuring complex family changes over time. This results in loss of the multidimensional, interactive, and evolving essence of the family (Fisher, 1982; Moriarty, 1990). Gilliss and Davis (1992) also cautioned that researchers frequently fail to address or make facile assumptions about family system effects and functioning without substantiating their presence. Other common areas of oversimplification that can lead to methodological errors occur when theoretical and conceptual issues are not considered, and when a single individual is chosen to represent the views of the whole family.

Kristjanson (1992) attributed problems with the ability of family research designs to measure family phenomena to the “incongruence between logical-positivistic methods” (p.37). She stated data produced by quantitative methods “are incomplete and do not capture the density and complexity of family systems theory” (p. 48).

Family caregiving

Family caregiving is the unpaid work of a family member that benefits another family member. It includes both an action and an affective dimension. This care may be a short-
term role following an acute illness or it may be an ongoing commitment in the event of chronic illness or disability. The primary family caregiver is the person who does the majority of this work. Glazer (1993) noted that it is usually a female family member, with men providing care only if a female member is not available. She noted that both men and women she interviewed believed health care of family members to be the woman’s domain. Family caregivers are often called informal caregivers in the literature (Abel & Nelson 1990; Glazer). However, the term implies occasional, trifling, tranquil, nurturing, reciprocal activities that do not match the essential care and hard work that many family members provide and will not be used in this paper. Caregiving activities include household work, care of dependent family members, social activities, and communication within the family and the community. Glenn (1994) stated that reproductive labour that includes caregiving and household work is central to the continued oppression of women. Women perform a disproportionate amount of this work allowing men to be more engaged in educational and employment advancement. Statistics Canada (1996) noted that women were 13 times more likely than men to cite family responsibilities as the reason for leaving their last job (pp. B2-3; B35). However, other scholars emphasize that caregiving should be celebrated as an essential, socially responsible activity that is fulfilling for many women (Abel & Nelson; Fisher & Tronto, 1990). Family members are often willing to be caregivers, but find the 24-hour-per-day care requirement and financial impact to be very stressful. Caregivers cite the primary causes of stress are lack of privacy, resurgence of old family conflicts, anxiety regarding their ability to provide the care required, trying to care for more than one household, physically demanding nature of the work, and having no personal time in which to regroup. Many caregivers admitted to feeling resentment and anger at having to change their patterns of living to adjust to caregiving demands, and then stated they felt guilty for feeling this way (Glazer, 1993; Kasper, Steinbach, & Andrews, 1994; Montgomery, 1988). Gordon (1991) succinctly captured the paradox that confronts women caregivers: How does one revalue and support women’s caring work without disadvantaging women?

### Impact of severe traumatic brain injury on the family

Severe traumatic brain injury (TBI) causes cognitive, affective, motor, and functional deficits. The extent of the recovery and rehabilitation following TBI are impossible to predict with any accuracy at the time of injury. However, individuals who experience severe traumatic brain injury (TBI) rarely recover their complete pre-morbid personality, abilities, or independence (Dikman, Machamer, Miller, Doctor, & Temkin, 2001; Warren, Wrigley, Yoels, & Fine, 1996). As a result, family members frequently assume some ongoing responsibilities for care or support of the injured individual. Given the relatively young age of the majority of individuals who experience a severe TBI, this responsibility and care may be required for many years.

### Quantitative studies

Several researchers concluded from quantitative studies focusing on caregivers who had a member who had experienced a moderate to severe brain injury that there was a significant and ongoing emotional impact on the family. The effects on family caregivers have been characterized as anger, anxiety, denial, distress, helplessness, passivity, caregiver burden, decreased quality of life, negative family relationships, and somatic disturbances (Baker, 1990; Florian & Katz, 1991; Wade, Taylor, Drotar, Stancin, & Yeates; 1998). However, Perlesz, Kinsella, and Crowe (1999) also noted that researchers have focused on families/family members who reported distress and burden. They have failed to highlight that a significant proportion of families and family members do not report high levels of psychological distress or dysfunction in either cross-sectional or longitudinal studies.

There has been some preliminary work done to explore the factors, conditions, and processes that explain the reactions of family members. The ability of individual family members and family units to cope following TBI has been attributed to several factors. These include: pre-morbid family functioning (Baker, 1990; Farmer & Stucky-Ropp, 1996); types of “brain-injured” families (Kosciulek, 1997; Kosciulek & Lustig, 1999); the behaviours of the injured individual (Brooks, 1991; Farmer & Stucky-Ropp; Florian & Katz, 1991; Perlesz et al., 1999); or the severity of the injury and the resultant cognitive, personality, and functional losses. Losses have also been identified in finances, lifestyle, and social activity (Brooks; Perlesz et al.; Wade, et al., 1998). Curtiss, Klemz, and Vanderploeg (2000) used the Couples Version of the Family Adaptability and Cohesion Evaluation Scales-II and the Coping Responses Inventory to examine change in family structure and coping at the time of admission to a rehabilitation facility. They noted a significant change in family structure following severe TBI, with pre-morbidly “balanced” type families experiencing the most change, moving from balanced, cohesive, and flexible to disengaged and over-controlled (p. 1121). However, in all cases, family members responded using similar ways of coping to those they had used in past situations of stress.

The study by Malec, Machulda, and Moessner (1997) provided some interesting insights as to differences in perception of memory, cognitive function, and depression between individuals with brain injury, a family member, and staff in a rehabilitation setting. Unfortunately, the researchers’ beliefs regarding the correctness of staff perceptions over those of the patient and family member marred the discussion. However, it does serve to highlight how different perceptions could influence relationships between these three key groups of individuals, and lead to conflict and miscommunication between individuals with brain injury, their family members, and clinicians.

Perlesz and colleagues (1999) have noted that the preponderance of studies regarding the impact of traumatic brain injury on the family have focused on cross-sectional data that provide only a “useful” snapshot of family impact at a specified point in time. Most of the studies are cross-sectional
family outcome studies carried out months or years after the injury during inpatient or outpatient rehabilitation. The majority of studies have utilized a self-report questionnaire or series of questionnaires. There has been little consistency in the use of instruments to measure family responses. As a result, it is difficult to compare outcomes even between studies of similar purpose and design. Several researchers have also focused on the critical care period. However, few studies have been conducted with families during the period between critical care and rehabilitation. In the studies of brain injury and the family, researchers have almost universally relied on the self-report of a single individual, usually the primary caregiver, and have concluded that this accurately represents the experience and needs of the family. “Family” is neither conceptually nor operationally defined in most research reports.

**Qualitative studies**

There are few qualitative studies in the area of severe TBI and family response. Only the study by Johnson (1995) focused on the family experience during the acute care period of TBI. She interviewed a total of seven family members that included the parents, siblings, and the individual who experienced the TBI. She conducted a phenomenological case study that focused on several key events reported from the perspective of the different family members. Johnson reported not only on areas of difficulty for the patient and family, but also positive transformations, including a deepened sense of family closeness, and a profound belief in prayer and spirituality. She also highlighted interventions the family members valued. Some were unexpected, such as intracranial monitoring that the family valued, as they perceived it was giving them feedback and reassurance about the patient’s condition. They also identified needs related to receiving understandable information and the relief they felt when the patient was extubated. The patient who experienced the brain injury described snippets of early memories, restlessly and repetitively wanting to go home, and the feeling of trying to piece things together during the period that followed coma. Unfortunately, Johnson’s study only followed the experience of one family.

Other qualitative studies have focused on the beliefs that family members had regarding the ability of the individual to hear and understand them, despite being in a vegetative state. Attributions of the patient’s willpower and family vigilance for improving patient outcome have also been studied (Whyte, DiPasquale, & Vaccarro, 1999). The mothers’ relationships and perceptions of their child after the injury, and their attempts to reconcile this with perceptions of their pre-injury child, were studied by Guerriere and McKeever (1997). Feelings of uncertainty, guilt, hope, loss of control/gaining control through information/learning the rules, wanting to be with the injured person, and searching for meaning were also found (Guerriere & McKeever; Plowfield, 1999).

The qualitative studies reviewed, although limited in number, provided a rich description of family member perspectives, study context, and the constraints of everyday life. In the case of the study by Carson (1992), it also provided a vehicle to examine the processes families experienced over time, and the phases involved in the experience of having a family member with a severe TBI, and to develop a theory for nursing practice.

**Methodological limitations**

Many researchers have highlighted the ongoing needs of both the injured individuals and their families during the acute care period following the severe brain injury of a family member. Unfortunately, there are several methodological and conceptual limitations that mar the value and utilization of knowledge in this area. Brooks (1991) noted that questionnaires designed and tested for individuals needed further testing with multiple respondents to establish validity and reliability before using them with families. However, in the studies reviewed, this was not addressed. He also noted the limitations of self-report data, lack of overall instrument testing for psychometric properties related to validity and reliability, lack of testing within this specific population, and over-reliance on this method of data collection. An enormous number of data collection tools have been used in an attempt to capture the experience of family members following TBI. They include: the Beck Inventories of Depression (Brooks, 1991; Perlesz et al., 1999), Brief Symptom Inventory (Wade et al., 1998), Duncan Index and Life Stressors (Wade et al.), Dyadic Adjustment Scale (Wade et al.), Family Adaptability and Coherence Evaluation Scales III, (Kosciulek & Lustig, 1999), Family Adaptation to Medical Stressors (Baker, 1990), Family Assessment Device (Kosciulek, 1997; Kosciulek & Lustig; Wade et al.), Family Environment Scale, Family Needs Questionnaire (Serio, Kreutzer, & Witol, 1997), Family Sense of Coherence (Kosciulek), and the Molter’s Critical Care Family Needs Inventory (Engli & Kirsivalli-Farmer, 1993). This use of multiple measures would indicate the recognition by researchers of the complexity of the family experience, needs, and psychosocial effects following TBI, but also the inability of quantitative survey methods to adequately quantify the impact. Additionally, Perlesz and others noted that the use of a large number of instruments on a small number of family members might provide convergence validity. However, it does not guarantee that any of the tools accurately and reliably measure family concepts. It can also be stressful for family members to have to complete several different measures. Another problem with questionnaires is that many of the tools are biased to measuring stress and burden, and families have no opportunities to provide responses that would be indicative of positive experiences or “uplifts” as opposed to burdens.

Other issues related to external validity of the vast majority of family research studies is the reliance on a single informant, use of volunteer informants, and informants who are recruited from families seeking the help or support of brain injury associations or outpatient departments. Additionally, small sample sizes, and the focus primarily on the period of outpatient rehabilitation limit the scope of our knowledge and understanding of families following TBI.

Brooks (1991) suggested that while studies have often used a within-group design to identify sources of variability within the population of individuals with varying severity of TBI, other control groups have not been used. This leads to the
impression that these effects are only an issue for families of individuals experiencing TBI. He recommended using a clinical control group to identify real differences for families of individuals with TBI. Perlez and colleagues (1999) noted that lack of consistency in conceptual and operational definitions of stress, burden and distress makes comparison of findings problematic.

Researchers of qualitative studies were uniformly better at providing conceptual definitions, stating a theoretical context, and choosing congruent methodology than were most of the researchers who conducted quantitative studies. However, several of the studies used exceedingly small numbers of informants. The phenomenology study by Johnson (1995) was notable in that it examined the experience of only one family, though it was one of the few studies that attempted to explore an approximation of a whole family’s experience.

Family research issues
There were no conceptual definitions of family and no rationale for why certain family members were chosen in many of the studies reviewed. Frequently, the researchers fell into the trap of equating the self-report of a single individual with family. Often in quantitative studies it was necessary to read the demographic data analysis to determine whom the researcher had included as “family” in their study. Perlez and colleagues (1999) observed that only a few studies have focused on relatives other than the primary caregiver, and none have focused on the family as a whole. Brooks (1991) noted that most studies took too narrow and traditional a view of the family. He also noted the tendency to support the views of family members over views of the patient, and the bias for simply seeing the patient’s perspective as unrealistic. Therefore, while many studies purported to be about family impact and outcomes following the TBI of a close family member, it was often a single caregiver’s perspective that was studied and reported.

Gaps, inconsistencies, and areas for further research
There are many gaps in the research and theoretical literature concerning families following the TBI of a family member. The gaps include failure to characterize family outcome over time, as the majority of studies have focused only on the rehabilitation time after discharge to the community. There is also a need to discover the tasks facing families at various points of the illness trajectory following TBI. Little work has been done with whole families rather than individual informants. Self-report questionnaires have been the dominant form of research. Therefore, studies using other research methods would enrich and strengthen the findings in this area.

Evaluation of family interventions, including community supports and public policies, is a huge gap in the research literature.

There are differences and inconsistencies in findings related to coping by parents and spouses across a variety of studies. Some studies have suggested parents cope better than spouses (Bailey, 1989; Ben Arzi, Solomon & Dekel, 2000), while others have suggested spouses are more “realistic” regarding outcome, and that this demonstrates greater ability to cope (Kreutzer, Marwitz, & Kepler, 1992; Willer, Allen, Liss & Zicht, 1991). Still others have found no difference between the psychological reactions of parents, and spouses (Wallace, Bogner, Corrigan, Clinchot, Mysiw & Fugate, 1998). There have been few studies that included siblings, children, or other relatives (Bailey; Gill & Wells, 2000). There are also inconsistencies related to family functioning and distress over time (Kreutzer et al.). Some studies have indicated that distress and problems in family function decrease over the first year, decrease after the first year, remain constant over time, or even increase with time (Perlez et al., 1999; Kosciulek, 1999; Marsh, Kersel, Havill & Sleigh, 1998; Moore & Stambrook, 1995; Watanabe, Shiel, Asami, Taki, & Tabuchi, 2000). However, Sanders, High, Hannay, and Sherer (1997) noted that despite high levels of caregiving responsibility, many families adjusted well following the TBI of a family member. Failure to use standardized measures across studies has made comparisons between studies with similar purposes difficult.

Researchers have used primarily descriptive or exploratory study designs that attempt to quantify the experiences, needs, and outcomes of families following the brain injury of a close relative. Many studies have identified ongoing needs of both patients and family members following brain injury. Despite a large number of studies in the area of families with members following TBI, much of the research is poorly conceived and structured, fragmented, and repetitive.

Study participants
Basic demographic data common to many studies of TBI were collected for participants and their families. Participant data included age, sex, type of injury, and injury circumstances. Family data included relationship to the injured individual, religious affiliation, and mother tongue.

The demographic data of the injured individuals and the causes of injury mirror those identified in the literature. There were seven males and four females who experienced a severe TBI in the study group. The ages of the injured participants ranged from 18 to 86 years. The mean was 30.2

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<th>Relationship of family member to the person injured</th>
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(Males 13; Females 12)
years, the mode 19, and median 21. All of the individuals under 50 who had experienced a severe TBI were involved in MVCs (seven vehicle collisions, two pedestrian/vehicle collisions) and the remaining two were individuals who had experienced falls. Alcohol intoxication was documented in 45% of the circumstances surrounding the injury occurrences. However, it was documented in only 18% of injured participants. In the remaining cases, it was the driver of the car causing the accident who had consumed the alcohol. It is often implied in the literature that the behaviour and judgment of the survivor had contributed to the injury. However, that was clearly not a significant pre-injury factor for the majority of the injured participants in this study. All the injured individuals whose families participated in the study were in a coma for more than two weeks following the injury with Glasgow Coma Scale scores of five or less (Teasdale & Jennett, 1974) and tracheostomies in situ for secretion clearance at the time of induction into the study. These are important indicators of the severity of the TBI sustained by the injured individuals.

As shown in Table One, the participants were primarily the parents, children, and siblings of the injured family member. While an attempt was made to include all types of families, there were no families presented to the researcher in which a spouse was the primary caregiver during the course of this study.

Families who participated in the study mirrored the rich cultural diversity of Toronto. The majority of families involved in the study were proficient in English and interviews were conducted in English with all families, except one. In this case translation was done by other family members or by a nurse from the unit who was proficient in the mother tongue. Additionally, there was some informal translation within the interviews by family members amongst themselves. Tables Two and Three illustrate the mother tongue and religious affiliation of the family members who participated in the study.

Data regarding religious affiliation were collected during interviews in which family members attributed spiritual beliefs and practices as either providing them with comfort and support or influenced the survival and outcome of the member who had sustained the TBI.

The initial interviews began with an introduction to the purpose of the study, the process of data collection, an invitation to participate in the study, and a review of the consent. I also introduced myself and outlined my experience and qualifications in this area. As Chenitz (1986b) noted, the interviewer must have the knowledge and skills necessary to gain the respect of the participants and understand the substantive area. This introduction was followed by a request to family members to tell me about the family member who had suffered the injury, and their family. Families were then asked to describe how they had heard about the injury and what it had been like for them since the injury, both individually and as a family. I listened closely to what was being said and also observed the tone and degree of fluidity of the discourse. I attended to body language and used many non-verbal cues and minimal verbal prompts to encourage family members to tell their story. I was conscious of ensuring that all family members had a chance to respond to questions, and soon discovered that perceptions and concerns sometimes varied markedly between family members, though the goals or intents were often remarkably similar.

Occasionally, when there was disagreement within the family concerning an issue, conflict would arise. As Schatzman and Strauss (1973) noted “There is no more important tactic…than to communicate the idea that the informant’s views are acceptable and important” (p. 74). It was often helpful simply to verbalize this principle to the family being interviewed, and ask that they give each other time to express their views. As a result, family members frequently voiced observations, questions, and concerns during the interview that they had not spoken of prior to the family interview.

Some family members remarked at the end of the interviews, or later during follow-up clinical conversations, how the meeting had opened up discussion within the family. Family members were also frequently curious as to how the study was progressing, and how the progress of their family and family member compared to others. They stated it was comforting to know that other families were in similar situations, experiencing similar problems and concerns.

During the transcription process, I had the opportunity to repeatedly listen to the responses of the participants. Responses with a lot of hesitations, rewording, and qualifications by the participants were the hardest to transcribe. However, frequently, such lack of fluidity in the discourse was a marker that the incidents being described had caused the person telling the story a great deal of stress, fear, or anger.

Code names were used during transcription to ensure confidentiality. I used an onomastikon, a dictionary of names, to choose code names that were consistent with the participant’s ethnic background. I also used a standardized system of varying code names (Monk, 1997). This system allowed me to recall or review contextual data during data collection.

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<th>Table Two: Characteristics of family members: Mother tongue</th>
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<th>Table Three: Characteristics of family members: Religious affiliation</th>
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The basic social process of negotiating emerged as the action part of the core variable that transcended the whole process families experienced during their relatives’ experience with PCU/MR. Negotiating reflects all of the discussing, exploring, dealing with, and navigating actions that family members do amongst themselves, with members of the health care team, and with individuals outside of the health care system, to understand the condition of the injured member, to promote their recovery, and to take action on their behalf. Negotiating begins when families learn of the TBI and continues throughout all phases of the process.

Negotiations between family members

Discussions between family members took a great deal of time, especially at the beginning of the process as roles, responsibilities, lines of communication, and resources were being arranged to accommodate the closest family members’ attendance at the bedside of the injured person, often for extended periods. Negotiations also included who would take over key facets of family life such as care of dependents, earning money, carrying out domestic chores, managing the affairs of the individual who was injured, making care and treatment decisions, controlling visiting, and contending with legal requirements. The following exchange illustrates the interaction between desired and negotiated roles and was determined by the pragmatic consideration of money.

Ania: I am here the most. I would like to be here all the time… I love her. She is my baby and I spoil her.

Natan: I would like to have a bed beside her. But I know she [the mother] would push me…to go to work.

Ania: You have to go to work because I am not working. You have to pay the mortgage. This is it (family interview, January, 2001).

While substitute decision-makers were legally designated, decision-making within the family was often contingent on past family decision-making practices and beliefs about illness, disability, and death. The process was negotiated within this context. Family members did not always agree about the decisions that needed to be made on behalf of the individual who had suffered the injury. One family member recounted decision-making responsibilities that he assumed that went against his family’s cultural tradition regarding social order. However, he had been responsible for the care of...
his father for many years prior to the injury. In this situation, many family members had come from abroad at the time of the injury, and the eldest son had made the initial decisions agreeing to surgery on behalf of the father. Then he returned home to a distant Canadian city.

The youngest son, who had power of attorney and who had deferred the initial decision-making to the eldest male family member, had a different perspective on the situation. He had taken over decision-making on behalf of his father when the other family members returned to their homes. He anticipated family conflict would be a consequence of decisions he was currently making because they transgressed the social order both within the family and the culture. He explained that within his culture there was great veneration of the family elders and that discussion of end-of-life decisions was a taboo subject. However, pre-injury dementia and other chronic health conditions of the individual who had sustained the injury made him question the wisdom of continuing aggressive treatment.

Even if I am the youngest son, I am willing to take charge of it…I want to do the best for my father and just do what would be his final wish. And if the rest of the family doesn’t like it, I have no problem just telling them where to go (family interview, September 2000).

Glazer (1993) noted in her work that female family members were most likely to do the unpaid care of family members, especially direct physical care, unless there were no female family members available. This trend for mothers and other female family members to be in attendance at the bedside was evident in this study. However, there were several families in the study in which the male members assumed the majority of the care, often due to the contingencies identified by Glazer. Care by male family members was also a consequence of other factors including stage of the family life cycle, family earning and work flexibility, and facility with English.

In this study, one of the wives who did not speak English was unable to provide bedside care because she was unwell, and there were children who required care. Therefore, the brother assumed the majority of the care. In one family, it was the father who considered taking early retirement to take on the primary role related to the ongoing care of his daughter, though care was undertaken together by both parents during the period of PCU/MR. It was a pragmatic decision as his pension plan and years of work afforded him the greater flexibility to pursue early retirement with only minimal penalties. In a similar situation, it was the father who spent the longest hours alone at the bedside with the mother making only episodic visits. The mother continued to work full-time and live out-of-town. In another family, it was the son who was expecting Dr. Kildare or Marcus Welby. A family member, had a different perspective on the situation. He had expressed a concern about the lack of relationship and follow-up that was given once the patient was transferred to the acute care unit from the critical care units. One father said, “I guess I watch too much TV…I was expecting Dr. Kildare or Marcus Welby.” A family member acknowledged an admiration for the skill and knowledge of the doctors and nurses, but he pinpointed his disappointment to a lack of compassion or connection.

The doctors ARE great and the nurses are wonderful. I mean you get the odd meathead… but if there is one thing that bothers me…it is the way everyone is so pessimistic…I mean okay, doctor, you come and talk to me and you tell me you don’t think [she] is going to wake up… but comfort me as well… you see me crying and you don’t care. You just leave the room (family interview, January 2001).

Therefore, in this study, while female family members were more likely than the male family members to leave work and other family and community responsibilities to be in attendance at the bedside to care for the family member who had experienced a severe TBI, the family decision was clearly based on the available family resources and who could be spared from other family roles and responsibilities. Occasionally, family members negotiated changes in who would be at the bedside, as the time spent in PCU/MR continued, or if family members came from abroad on an extended basis to assist with family tasks.

In two of the families, there were no other family members to negotiate with on an ongoing basis. Without a doubt, these two women had the most difficult time assuming all the care at the bedside while trying to meet other obligations outside the hospital. However, it was important to look for the strengths these women had attained in overcoming previous adversity, as they displayed remarkable resilience in this situation despite limited resources and social support (Anderson, 1994).

**Negotiating with members of the health care team**

Family members often had conflicted relationships with members of the health team. Most had an abiding admiration for the illness care offered to their family member and were grateful for the emergency and intensive care that allowed their relative to survive the initial injury. One family member stated:

Until I came in here, I never realized. I mean they really are caregivers… when you think of nurses and doctors you have a respect for them because they treat people in need, but I just have a different view of them now (family interview, December 2000).

However, members of all families interviewed articulated some disappointment in the overall expressions of concern, interest, and support they received from members of the health care team. All families interviewed had one or more members tell of an incident of being given little or no hope for survival or recovery. Members of each family expressed frustration in the lack of relationship and follow-up that was given once the patient was transferred to the acute care unit from the critical care units. One father said, “I guess I watch too much TV…I was expecting Dr. Kildare or Marcus Welby.” A family member acknowledged an admiration for the skill and knowledge of the doctors and nurses, but he pinpointed his disappointment to a lack of compassion or connection.

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While this is a study of families and their concerns and actions during the period of PCU/MR of a close family member, it is interesting to juxtapose an examination of the work structure that is present in the acute care setting. The narrative of a medical resident who was a member of the trauma team during the time this study was in progress appeared in a Toronto newspaper. Maskalaky (2001) wrote an account of a day in the life of a trauma resident. In addition to the grinding pace and the uncertainty of who and what was coming through the doors of the emergency room, he also recorded the effect this on-call system of work had on his ability to make human connections.

*I am often asked how it is possible for someone to do an important job, one that requires mental faculties, after being awake 30 hours at a time. Many question the safety. I try to explain that the last thing that goes is my ability to do my job. I can sort out someone's high potassium at 5 in the morning. What I lose is my ability to do it as myself. I am not funny, I am not eloquent. I have no capacity to make my empathy felt. My body simply wants to make the diagnosis, lie down, and shut down (p. D4)*

Family members or family representatives were invited to attend certain meetings that were scheduled on an ad hoc basis, usually in response to the team’s need to make care decisions or organize discharge and transfer. At these meetings, family members were usually greatly outnumbered by members of the health care team. As Strauss (1978) indicated, this imbalance produced a power discrepancy that reinforced the social order. While family members appreciated an introduction to the team and the explanation of their roles in working with their relative, family members persisted in their beliefs that it was the attending physician who was the most knowledgeable and skilled in improving the health outcomes of their relative.

The team provides several layers of distance between the family and the attending physician. Usually the staff nurse is the first point of contact with family members. Concerns voiced by family members may be carried up the social order ladder from the nurse to one of the advanced practice nurses or therapists. It may be answered at that level or proceed up the hierarchy to the interns or resident, or the nurse practitioner. Again, it may be answered at this level, or may proceed to the attending physician through this intermediated process. The concern may also be dismissed at any of these levels, or communication may not be relayed back to the family member that posed the question. This system of protecting the time of the attending physician again reinforces the existing social order within acute care facilities.

Collectively, the nursing staff has the most intense relationship with patients and their families. While other medical and health care staff may be on call, only nurses provide continuous 24-hour patient care, assessment, and monitoring. Unfortunately, frequent shift rotation, coupled with the nature of the work assignment on both the acute care nursing units in the study, resulted in the assignment of nurses to patients based on workload and room numbers rather than on continuity of care or promotion of patient and family relationships. One family member described the assignment of the nursing staff as the *nurse du jour*. This method of work assignment reflects a value on the functional aspect of what Strauss (1978) termed “body work”, and fails to recognize the importance of establishing the kind of trusting relationships with family members that are so crucial in times of serious illness, and the kind of critical thinking that is so essential to improving patient and family outcomes.

In clinical conversations conducted during the study and recorded as field notes, nurses often noted that patients in PCU/MR had the highest acuity of care of all the patients on the unit due to complete dependency, multiple tubes, and many medications and treatments. Additionally, family members often had many questions and needed a tremendous amount of support. As a result, nurses frequently welcomed a change in assignment away from these patients that allowed them an easier day with less responsibility (field notes, January, 2002).

The nurses were often in the unfortunate position of bearing the brunt of the family’s dissatisfaction with the system. Furthermore, some nurses resented the “interference” and “added work” some family members represented. Also, there was no tangible reward to providing family-centred care, except for the appreciation of family members. In a recent clinical conversation, one nurse noted:

*A few of us get labelled as being good with ‘difficult’ families, so we get more of the hard assignments than some of the others, or we’re criticized by other nurses for being too soft on families, and letting them break the rules (field notes, January 2002).*

Finally, when family members are at the bedside 24 hours a day, staff nurses feel that they are constantly under observation and subject to family demands, even when staffing levels are minimal, such as on night shift. One nurse explained:

*Families think it is the same on nights as on days, like in critical care. But here it is different. I have three patients on days and six on nights...maybe three with trachs. Sometimes they have to wait (field notes, November, 2001)*

Additionally, on night shift, staff and family members may compete for quiet places to take a break, such as the lounges on the units (field notes, January 2002).

In observing the work process on the units in which the study was carried out, it was apparent that the staff nurse was the only member of the health care team who was always attendant on the patient and the family. All other health team members visited the patient and family on an episodic basis. Only the staff nurses were charged with the continuous care and monitoring of the patient. The continuous care of patients made the nurse the most available member of the team to the family. However, the continuous nature of the assignment meant that the nurse was the least able of all health care team members to attend family meetings, educational upgrading sessions, or professional meetings. On one of the units in the study it was observed:

*The trauma team meets twice a week to review the care of the patients on this service. The entire team of social workers, physiotherapists, occupational therapists, the*
speech pathologist, the patient care manager, and the charge nurse attend the entire meeting, even if they have no assigned clients to be discussed. The meeting can take upwards of an hour. However, staff nurses have small, ‘walk on’ parts. The staff nurse who is charged with the care of the patient on that day presents the patient situation. The staff nurse may have cared for the patient once or many times. The assignment is made on a nurse du jour basis. The staff nurse perches on a chair or stands at the door. The staff nurse may be interrupted or questioned by any of the other personnel present. The nurse is dismissed after the patients assigned for that day have been discussed (field notes, November, 2001).

At an educational function concerning the legal issues of trauma care, virtually the entire health care team, except medical staff and nursing staff, are in attendance in the audience. They were given paid time off to attend. (field notes, October, 2000).

Staff nurses were clearly at a social and professional disadvantage in both these situations. They were placed in the awkward position of presenting the patient situation to other team members who have worked with the individual and their family since admission, in the case of social work, and since admission to the Neuro-Intensive Care Unit (NICU) for the nurse practitioner and therapists.

In the second situation, staff nurses were an invisible member of the team, unable to enjoy the benefits of professional development or a free lunch. Lack of attendance did not indicate a lack of interest or professionalism by the nurses. Many more staff nurses on the units were engaged in professional development working on neuroscience certification courses, and post-diploma or graduate degree courses than were the other professional staff members. However, time off for these courses had to be arranged by the individual nurse by switching shifts with others or taking vacation time.

When examining the social order within the acute care setting, it was apparent that despite their skill and knowledge, staff nurses held a relatively low ranking in social order. Part of this may be attributable to their failure to achieve their full potential of independent decision-making concerning care. This may be due to lack of continuity of patient assignments that would allow nurses to gain a rich understanding of patient and family perspectives and address their needs and concerns. The other consideration was that many actions or approaches that were suggested by the nurses had to be sanctioned as orders by the medical staff or the nurse practitioner, thus placing them in a dependent position. However, many of the nurses were unwilling to have more continuity and accountability for patient care as they believed this would increase an already heavy workload.

While increasing the continuity of care and independent decision-making has the potential to improve the overall ability of the staff nurse to deliver patient and family-focused care, a few family members on each of the units in the study noted that there were staff nurses with whom they would not have chosen to have a more lasting relationship. A family collaborated on relating the following concern:

Ulagan: Since we have been here, we have seen so many dedicated people. But some treat [him] badly…

Sarala: They are always annoyed and complaining. In [his] position he is unconscious. He doesn’t know what is happening, he can’t call the nurses if his IV or feeding bag is empty…

Ran: So whoever looks after him needs to be dedicated. I happened to speak to one nurse… she said, “Oh my God, I hate my life…”

Sarala: Some nurses talk to him, even though he is unconscious. Some just wash him (family interview, November, 2000).

Therefore, while family members wished for lasting, predictable, professional relationships, continuity was seen to be desirable only with nurses who were committed and patient-focused in their approach to care. Advanced practice nurses, to some degree, filled in the gap in continuity of both medical and nursing care. However, they were frequently spread too thin, and had too little system support from either medicine or nursing to make their position tenable. During the course of this study, one of the CNS/NPs who left the acute care unit has not been replaced. In clinical conversations, staff and charge nurses frequently remarked on how significant a loss it is to continuity of care and family-centred care. The family member who coined the term nurse du jour commented:

I hardly ever see the doctors… the best line of communication for medical stuff is the nurse practitioner… I only found out about her three weeks down the line… She’s a bit hard to get hold of… She’s very busy… but each time we talk, she just takes off… there’s not much two-way communication. Not much of the topics I want to talk over… I think the idea [nurse practitioner positions] is good, but they need to have about a dozen of them around here (family interview, October 2000).

Family members interacted and negotiated care with many other health care personnel. However, very few members of the health care team, other than nurses and doctors, were mentioned in family interviews or clinical conversations. One family member remarked on the role of the emergency department volunteer, another on a speech pathologist and the occupational therapist, two mentioned the work of physiotherapists, and three commented on the assistance provided by social workers. Most family members found the multiplicity of team members very confusing and stated they had learned about the functioning of the health care team by “osmosis”. Most family members believed the physician or nurse practitioner determined the care decisions on the units. A family member noted:

It would help if the system could be explained somewhere early in the process so you have some names and some contacts and you know who’s who. They all dress the same and you can’t tell a nurse from a physio from a doctor from a respiratory therapist (family interview, October 2000).
While the team very often did introduce themselves and their roles to the families verbally both at the bedside and in team meetings, family members found it difficult to take in and remember so much information that was given verbally. Members of the health care team often expressed their frustration when family members confused roles and information given. Again, examining the structure and value of the work in acute care revealed there is little value placed on providing explicit information given to families concerning the process, procedures, and personnel. Therefore, it was not surprising that family members had difficulty negotiating the hospital system and processes.

Additionally, the nurse practitioners and social workers in both hospitals were faced with the need to move patients through the system due to the need to make the “bed” available for other patients. As there were insufficient rehabilitation and long-term care spaces available, especially for slow stream acquired brain injury rehabilitation, transfer was often arranged to community hospitals, closer to the patient’s home, as an interim measure. This need to move patients out of level one trauma facilities was often not positively perceived by the family members. Nurse practitioners and social workers were placed in the uncomfortable position of trying to promote optimal care and provide support to family members while seeing them rapidly out of the door, sometimes to less-than-optimum care situations.

In summary, family members were overtly welcomed to the hospital and told they were an integral part of the care and healing of the individual who had suffered the severe TBI. However, in practice, there were few tangible supports put in place and little information was prepared that was understandable to the layperson. The input and presence of family members were tolerated within system-defined limits. The hospital procedures, personnel, and processes were not made explicit. Family members had the most access to nurses on an ongoing basis. However, staff nurses had the least status on the health care team. The attending physician occupied the highest status in the social order hierarchy on these acute care units, followed by the nurse practitioner.

Family members were often afraid to challenge the system by voicing their concerns due to fear that it could cause negative repercussions to their relative who was so vulnerable. This hesitancy to address concerns for fear of negative repercussions was consistent with Bailey’s (1989) findings in working with spouses and siblings of individuals with acquired brain injuries. In general, family members who were willing to accept hospital procedures and processes, “focus on one day at a time”, and those who had a lot of family and individual supports outside the system managed better than those whose support needs, desire to get involved in determining care, or requests for information exceeded the system norms.

**Negotiating with others**

There were many other people outside the health care team with whom family members interacted as a result of their relative’s injury. Depending on the circumstance of the injury, these included: lawyers, insurance adjusters, case managers, other patients’ family members, and clergy. Action taken to find and hire lawyers and case managers also required a lot of negotiation through uncertain territory by family members. Most people had never hired a lawyer or heard of a case manager. They were provided with names of lawyers who specialized in personal injury. However, outright endorsements are not considered ethical, so families were advised to make appointments, call several, and interview a few before deciding. Some family members did not initially see the need for these services. However, the role of the independent case manager, in particular, was of great benefit to families as they tried to understand the complexities of the whole system in order to act and advocate on behalf of the individual who was injured throughout all phases of healing and all health care settings. A good case manager, independently hired by the family, was an essential element in reducing uncertainty. In Ontario, the services of a case manager are required by law for individuals who suffer a catastrophic brain injury (Bill 59).

In injury situations in which insurance settlements were not available, family members expended significant time and effort to sort out system intricacies and options. One family member discussed their experiences negotiating on behalf of the injured family member.

*Lisa is going to look after everything. She is the case manager from our side. She will ensure everything benefits him [the patient]. Originally, the insurance company arranged the case manager. Then we decided to go through a lawyer. We wanted to have our own case manager… to get proper payment… otherwise the insurance company will screw you* (family interview, November 2000).

While the family member’s expression of distrust of the insurance company initially appeared somewhat extreme, field notes revealed an incident with another family in which an insurance adjuster came to the hospital to see their relative. The adjuster stated she had received conflicting reports as to whether the patient was awake or still in a coma. She insisted on entering the patient’s room to “see for herself” after requesting the permission of a family member. The adjuster entered the isolation room abruptly, unprotected by a gown, mask, or gloves. She observed the patient’s eyes were open but unfocused. The patient had a decorticate posturing response to stimuli. She was in a state of PCU that was clearly unfamiliar to the adjuster, who departed still confused as to whether the patient was awake or still in a coma. Later, the family member related how they had seen a man in their backyard the previous week trying to photograph another family member through the window who had also been injured in the MVC. They had assumed that the insurance company employed the photographer.

Police officers were involved with the cases in which there were criminal charges associated with the causes of the injury. Often, when the individual who was injured was not at fault, and the person who caused the collision was impaired or driving in a negligent manner and was not injured or only minimally injured, family members had difficulty coming to
terms with the injury. Unfortunately, police investigations and court proceedings can be prolonged, and often provided “one more thing… like the straw that broke the camel’s back” with which family members had to deal. They perceived that the person who was responsible was living without consequence while their family member had suffered a critical and likely permanent injury. A family member remarked:

“We’ve got these court dates… so the emotional attachment to this situation… feels like it will go on forever” (family interview, February, 2001).

Hospital support groups and other families who are in similar situations also provided informal information and support through shared experiences. In many illnesses, speaking to other family members who have a relative who has suffered a similar situation or condition and who is further on along the illness trajectory provides family members with a chance for vicarious learning or “rehearsal” (Strauss, Fagerhaugh, Suczek, & Wiener, 1985, p. 28). However, due to the highly individual nature of the injuries and imperfect understanding of the other family members, information gathered in this manner may be of varied use, accuracy, and assistance. One family member stated that when he compared the progress of his relative to others he was “very proud” she was “holding her own” (family interview, December, 2000). However, another stated sadly, “so many families have come and gone in the last three months… and we are still here… not ready for rehab” (family interview, January 2001).

**Negotiating the health care system**

Navigating and understanding the process involved in hospital care is one of the most difficult aspects for families to negotiate. Some policies can be seen to be contradictory from the family’s perspective. For example, at one of the hospitals in the study there are signs posted in strategic locations of the hospital, such as the main entrance and the elevators, professing the hospital’s commitment to patient-focused care and the transformation of the health care system. However, another sign outside the acute care unit states families may not stay at the bedside overnight. The message on the sign notes the rooms are small and that other patients need their privacy.

It was difficult for family members to reconcile the actual hospital practices with the professed philosophy and feel secure while navigating their way through the health care system. On both acute care units used in the study, there were signs posted telling family members that they could not sleep in the family lounges or shower on the units because the facilities were for patient use only. However, family members, abetted by sympathetic staff members, frequently transgressed these rules because they were compelled to provide support and presence. One family member remarked on how, after being told to go home, he felt he was drawn back to the bedside.

Sometimes I go home to sleep and I try to go to sleep. But at 12:45 in the morning I go back to the hospital and stay” (family interview, January 2001).

During the process of PCU/MR, family members negotiated with many different people through the hospital settings of the emergency room, critical care units, and the acute neurosurgical units of the hospitals. For individuals who spend an extended period of time in PCU/MR, they also faced transfer to a community hospital or long-term care facility to await “rehab readiness”. For most family members, the hospital settings, processes, and people were unfamiliar to them at the time of the injury, and they had a steep learning curve with few signposts or guides along the way.

Relatives of those patients who made a steady and fairly rapid improvement faced a great deal of uncertainty as they negotiated relationships with the health care team in a variety of settings. However, the negative effects were mediated by a sense of progress, and eligibility for acquired brain injury rehabilitation programs. Family members whose relatives made slow progress following the TBI experienced more uncertainty concerning recovery and the potential for rehabilitation. They often had to learn to navigate the health care and insurance systems to be able to advocate effectively on behalf of the injured member, especially in regards to treatment and placement options. However, they had less uncertainty regarding health care settings and relationships.

Families in which the relative who was injured remained for weeks or months in a state of PCU/MR often had the most difficulty *making it better*, despite stable health care relationships and settings, because there were few placement options open to them offering any hope for future recovery. This refusal to accept the status quo was especially true if the injured family member was young. Older individuals, especially those who had other health problems, generally followed very minimal trajectories of recovery, unless their injuries were limited focal injuries caused by falls.

Establishment of meaningful health care relationships and access to acceptable resources and settings for recovery were also important factors that impacted on the family. Those family members who made a meaningful connection with one or more members of the health care team expressed more comfort with care decisions, and felt that the best possible outcomes had been achieved.

Unfortunately, in this study, as with Chesla’s (1997) phenomenological study of 130 nurses in critical care areas, family-focused care was not given priority during the acute phases of an individual’s illness, especially if the individual was slow to recover. Instead, the greatest priority was given to biomedical skills and tasks. However, even the rationale for these tasks and procedures are not made explicit to family members. The process of negotiating in the study was also consistent with Thorne’s (1993) theory of *Negotiating Health Care*, with family members experiencing *naive trust*, followed by *dissenchantment* and, finally, *guarded alliance*.

Family relationships and resources were also important factors. Those with a close, strong, supportive family nucleus were most able to absorb the impact of injury. Members were able to offer each other support, share financial resources, distribute care and decision-making, and provide respite and
relief. Usually, they were also the most able to provide vigilance, care, support, stimulation, and advocacy on behalf of the individual with the injury. As a result, they were most able to influence the trajectory of recovery.

As Wright and colleagues (1996) noted, “illness is a family affair” (p. 288). In this study, the severe TBI of one family member impacted the entire family and the entire family experienced the illness alongside the patient. There was a general pattern of concerns and a progression through the process of understanding and coming to terms with brain injury. However, families have distinct structural, developmental, and functional components. The family experience of TBI was as diverse as the families themselves, and the families were as diverse as their members.

Families are not an amorphous mass. Families are composed of individuals who have personal needs and perspectives that are distinct from their family roles and responsibilities. Participants in this study shared their individual, as well as their family member perspectives on the experience. The various strengths and perspectives that individuals brought to the care of the injured individual enriched families and the injured individual. However, the implication of recognizing that the family cannot be defined by one member is that the health team must work with all of the family members involved in the care of the injured individual and not rely solely on a family spokesperson to represent the family’s perspective.

Families that were divided through prior separation, divorce, or past family grievances, or those who had significant disagreements concerning care decisions, were least able to provide each other and the injured member with the tangible and intangible means of support needed during this period. Even when individual family members tried to offer support to the individual, disagreements within the family often precluded a sense of achievement or cohesion. Wright and Leahey (2000) noted families that had experienced a divorce were under enormous stress and spent increased effort to accomplish family tasks, especially in regards to “physical maintenance, social control, and tension management” (p. 117). The injury of a family member compounded feelings of pressure and impact on the family members.

It became apparent during the study that the injury caused a significant impact on family functioning. Most of the individuals with injuries were adolescents or young adults. These families found themselves forced to make transitions that were reminiscent of earlier stages in the family life cycle. This was especially true of families in which the individual had already “been launched” and the parents had “moved on” or were in the process of doing so. They suddenly found themselves again adjusting family systems to accommodate care evocative of infancy and early childhood.

In families in which the injured member was a parent, changes often involved an abrupt role reversal between parents and adult or adolescent children that is more common in later stages of life, which includes the care of older family members. When the injury affected a family member whose income was significant to the family’s financial resources, families had to change work-related roles, as well as making changes to other instrumental and expressive functions. Additionally, if one or more family members centred all their time and energy on the injured person, other family members experienced an additional sense of loss because of the missing instrumental and affective functions that this person usually performed.

Wright and Leahey (2000) defined instrumental functions as those aspects of family functioning that relate to activities of daily life. These take on a greater significance when a family member becomes ill or disabled. Initially the family is the only link with the pre-morbid personality, preferences, and abilities of the individual.

Available, ongoing health resources were contingent on both the age of the patient and the circumstances surrounding the injury. Those 18 and under had the best access to rehabilitative and slow-stream rehabilitation covered by the provincial programs.

Individuals who had been injured in a circumstance in which they were eligible for an insurance settlement also had greater access to equipment and services than two individuals who were injured under circumstances in which there was no insurance claim. None of the injured individuals had long-term disability insurance benefits. Throughout the study period, families were still involved in processing insurance claims. Especially at the beginning, there was little money forthcoming from the insurance companies, and some family members were in financial straits that increased their feeling of stress. However, even when there was some access to interim money, family members were often reluctant to spend it “in case it was needed later”.

Negotiations between family members, members of the health team, and other individuals representing insurance companies, law enforcement, and the legal system were ongoing. However, the processes involved were rarely explicit. Family members walked a fine line between advocating for their relative and alienating those in power. Families often saw resources for long-term care and slow-stream rehabilitation as being inadequate or unsuitable, and transfer to facilities outside the acute care hospital were frequently breaking points for families.

**Conclusion**

Detailed family assessment is needed to understand how members are actually processing the experience of having a family member with an uncertain trajectory of recovery following a severe traumatic brain injury. From this vantage point, it becomes possible to determine, in partnership with family members, their needs and what interventions are required. There was a great deal of variation between families and even family members within the same family. Therefore, it is important to work collectively with all the family members who are involved in the care of the injured individual, rather than a representative individual. Study findings highlighted practice issues related to limited family assessment, inadequate communication and support, lack of continuity of care, and the need for an increased role for
advanced practice nurses in order to improve family- and patient-centred care following the severe traumatic brain injury of a close family member. Detailed recommendations for practice were previously published in AXON (Duff, 2002).

The study findings also called attention to the degree to which family members relied on neuroscience nurses to support, educate, and guide them through the difficult period while their relative was in a state of post-comatose unawareness or minimal responsiveness. They were impressed by our knowledge and skills related to neuroscience and complex care. However, it was our willingness to be open to their pain and suffering and the small acts of kindness or compassion that were recalled by family members as being essential to establishing trust not only in our expertise, but in our compassion and humanity.

About the author

Diane Duff, RN, PhD, is an Assistant Professor in the School of Nursing at York University in Toronto. Comments or requests for further information may be directed to her at dduff@yorku.ca or addressed to Diane at School of Nursing, HNES 338, 4700 Keele Street, Toronto, ON M3J 1P3.

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